ALTERNATIVE STORIES ABOUT A GIRL WITH AUTISM SPECTRUM DISORDER

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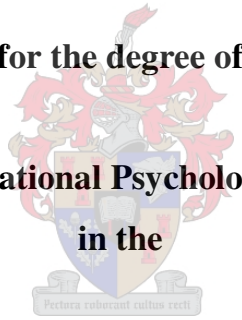

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at

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DECLARATION

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ABSTRACT

In this research voyage of discovery, we story the voices of me (the research inquirer), my family and a teacher about our experience with a young woman with Autism Spectrum Disorder – my youngest sister Leyna.[1] This is our attempt to give Leyna and (dis)ability a voice. Their voices have been silenced from research for too long.

I try to explain a narrative research lens as a foundation for this document – one that views autism not as a disorder, but as a difference that needs to be embraced. People often live their lives according to the problem stories they tell themselves, and do not see the alternative stories that surround them every day. On this voyage I therefore tell our story to document the inspirational experiences that people with autism bring about in the lives of those supporting them. Little research that focuses on alternative stories about autism has been done on a global scale. Moreover, little research has been done on autism specifically in the South African context.

This thesis relates the stories of the people involved in caring for my sister with autism. It brings a message of hope and suggests possibilities for future research voyages about autism.

[1] Pseudonym has been used

OPSOMMING

In hierdie navorsingsontdekkingsreis vertel ons 'n storie deur verskeie stemme te laat hoor: ek, die navorsingsondersoeker, my gesin en 'n onderwyseres vertel 'n storie oor ons ervaringe met 'n jong vrou met Outisme Spektrum Versteuring – my jongste suster Leyna.[2] Hierdie is ons onderneming om vir Leyna en gestremdheid 'n stem te gee. Te veel stemme is al te lank deur navorsing stilgemaak.

Ek probeer die narratiewe navorsingslens te verduidelik as 'n grondslag vir hierdie dokument – een wat outisme nie as 'n versteuring sien nie, maar eerder as 'n verskil wat aangegryp en gerespekteer moet word. Mense leef dikwels hul lewens uit op grond van die probleemgesentreerde stories wat hulle aan hulself vertel, en sien nie die alternatiewe stories raak wat hulle daagliks omsluit nie. In hierdie reis vertel ek dus ons storie om die inspirerende ervarings wat mense met outisme in die mense wat hulle ondersteun teweeg bring, te dokumenteer. Min navorsing wat op die alternatiewe stories oor outisme fokus is tot op hede op 'n globale skaal gedoen. Verder is daar nog min navorsing oor outisme spesifiek in die Suid-Afrikaanse konteks gedoen.

Hierdie studie vertel die stories van die mense wat betrokke is in die versorging van my suster met outisme. Hiermee word 'n boodskap van hoop gebring en moontlikhede voorgestel vir toekomstige navorsingsreise oor outisme.

[2] Skuilnaam is gebruik

ACKNOWLEDGEMENTS

I wish to express my sincere thanks to the following people:

To a loving God who gave me purpose in this life, placed me in a safe and caring family and made me see others through His eyes. Thank You for all the blessings in my life!

To my sister Leyna,* for accepting me for who I am and changing me for the better.

To my mother, father and middle sister, for loving me, believing in me and supporting me through all my ups and downs. Thank you for your willingness to help me write down our story.

To Professor Rona Newmark, my supervisor, for taking on this research voyage with me and believing in this study. Without you this would not be possible.

To Sam and Sarah Cruce, for helping me see and understand autism through your eyes.

To my boyfriend and all my friends who supported me and understood that I did not always have time for them. I will make it up to you!

To my language editor and the technical editor, thank you for making sense of it all!

Thank you all from the bottom of my heart!

Christelle

TABLE OF CONTENTS

LIST OF FIGURES

Part 1

The story behind the story: An introduction to my research voyage of discovery

> *"Narrative research is a voyage of discovery – a discovery of meanings that both constitute the individual co-storyteller and are co-constructed in the research process."*
>
> *(Josselson & Lieblich, 2003, p. 259)*

How does one begin to write about something that one struggles to grasp oneself? How do I convey to you the stories so that you (and I) come to a fuller understanding of the influence that someone with autism spectrum disorder[3] can have on your life? And how do my co-narrators and I give a voice to the person whose voice has been unheard for so long? I want to emphasise the above quotation as I try to explain my stance towards the research voyage – a voyage of discovery where I endeavour to answer these heartfelt questions. I want to invite you to read her story – *our* story – and get to *know* her. I know that you will never be able to know her as we, my family and I, know her. Will any of us ever truly know what she is thinking, feeling, hoping?

My wish is that by writing this story, you (and we, the storytellers) will hear her voice in some little way, and learn to (really) listen to what she has taught us. I also hope that this will be the beginning of an even greater research voyage that gives voice to those whose voices have been unheard for so long. This section will provide the lens through which my research voyage is viewed, and equip you to discover, with me, the alternative stories that exist when living with a person with autism.

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[3] The terms 'autism' and 'autism spectrum disorder' are used interchangeably throughout this document. Autism (also called Autistic disorder) is a condition on the autism spectrum together with Asperger's syndrome, Rett's disorder, Childhood disintegrative disorder and Pervasive developmental disorder, not otherwise specified (American Psychiatric Association, 2000). The spectrum refers to the many different forms of autism that do exist, and acknowledges the uniqueness of each individual with this diagnosis. In this document, it is important to note that I use them both interchangeably as referring to the same meaning. The definition of autism / autism spectrum disorder is discussed in depth in part 2.

My interest in this voyage of discovery

My youngest sister, Leyna,[4] was diagnosed with autism spectrum disorder 16 years ago. It has not been an easy road growing up with her, as many people living with family members with autism will agree. This is also evident in the research studies on autism, where the focus has been mainly on the problem-saturated stories that autism adds to family dynamics (e.g. psychopathology and family stress) and other contexts such as the school environment (Mash & Wolfe, 2005; American Psychiatric Association, 2000). However, I would not exchange the experience that I have had with my sister, or the knowledge and insights that I have gained from living with her, for anything. Realising this, I have been very curious to know whether I am the only one who feels this way – who views her influence on my life as a miracle and an inspiration – moulding me for greater things and making me see life in a completely different way. Furthermore, I wondered that if this is the case, if this could not be a way of giving her a voice, as she is unable to do it herself.

This is how I became interested in researching the effects of a person with autism on the life stories of people surrounding her. This respectful curiosity, i.e. to find out about life stories and the meaning that people attach to their specific stories, relates closely to the narrative way of thinking. Growing up, I especially liked to think of my life as an ongoing adventure, with everyday events building my life story. That is what I like to think of as the definition of a narrative research approach as I try to conceptualise it. Working within this approach, I have changed some technical terminology that is used in traditional, scientific research studies to preferred narrative terms. To rule out any confusion, the research design in this document is referred to as the *plan of inquiry* and the different research methodologies as *modes of inquiry.* The *research problem* is called *research curiosity,* the researcher the *inquirer* and the participants are referred to as my *co-storytellers* or *co-narrators*. When referring to data analysis, the term *making meaning of the stories* is used. In addition, the term 'data' is not used, as I rather speak of the *stories that are told or gathered*. Writing up the stories gathered in narrative terms is called *documenting* and the research

[4] Her name has been changed for purposes of confidentiality. The name Leyna was chosen, for it means 'little angel' in German and 'bright and shining light' in Russian ("Meaning of the name Leyna and etymology of the name Leyna", 2008).

interview is referred to as a *discussion*. Now that we have an understanding of the terms used, let us take a closer look at stories, as this is what narrative research is all about.

According to Morgan (2000, p. 5), "stories are central to an understanding of narrative ways of working". Furthermore, for narrative inquirers, the word 'story' has a definite meaning, and denotes "events that are linked in sequence, that happen across time and according to a plot" (Morgan, 2000, p. 5). The underlying belief is that people form their own stories and make meaning of life through events and experiences: "A narrative is like a thread that weaves events together, forming a story" (Morgan, 2000, p. 5). Unfortunately, people often make meaning of their lives through negative, problem-saturated stories and "the meaning of [their] life events comes from the stories that [they] tell themselves and each other about those events" (Freedman & Combs, "Narrative Worldview"). The narrative inquirer, however, believes that "there are many experiences in each of our lives that have not been storied … Each of those events could, if storied, lead to a different, often preferable, life narrative" (Freedman & Combs, "Narrative Worldview"). In other words, they seek for alternatives with the co-storyteller to narrate new, encouraging stories.

These alternatives are sought out by listening carefully in a respectful manner and asking questions about life events. By asking questions in a non-threatening way, narrative inquirers have specific intentions and several purposes when a co-storyteller tells their life story. According to Freedman and Combs (2008), questions are asked to generate experience to inquire about those details that might enhance experiential involvement. They (the co-narrators) then tell the inquirer in response about "events and the meaning of events, developing them into memorable and vivid stories" (Freedman & Combs, 2008, p. 2). Therefore, the inquirer and the co-storyteller develop "richly described story lines that extend over larger stretches of time" (Freedman & Combs, 2008, p. 3) and contribute to meaning making. I used the above-mentioned conversational techniques from narrative inquiry to assist and facilitate my research voyage. I hope that, by narrating my own and the co-storytellers' alternative stories, it will have an effect on others' life stories about autism.

Research curiosity and the research purpose

As mentioned previously, little research has been done on the positive attributes (alternative stories) about autism, especially within the South African context. Studies of this nature have been done in other countries. Ferguson (2002, p. 129) states that "[m]ost research on families of children with disabilities tend to gloss over the situational and cultural complexities that surround all of us … and always (have) negative responses of parents of having a child with a disability". However, in his study Ferguson (2002) found increasing recognition and growing research that a significant number of parents actually report numerous benefits and positive outcomes for their families associated with raising a child with disabilities. Furthermore, Fleischmann (2004), after analysing narratives of parents of children with autism, found three themes emerging about the positive influences of their children on their lives – i.e. parental empowerment, a more positive, strength-based worldview and the empowerment of the child. Findings like these show that there is still a gap in the knowledge base of South African research regarding families' views on autism. Billington (2006, pp. 10-11) states that autism spectrum disorders have captured much attention from professionals as well, because of "the questions posed by autism and their capacity to strike at [their] very heart … for they are questions which challenge [them] to contemplate their own minds and their own consciousness". It will thus be of great value to story these questions in order to create a platform in South Africa for stories about autism as an alternative to problem-saturated ones. Hence, the study will be guided by my own research curiosity about the following:

> What are the alternative experiences or influences that the girl with autism spectrum disorder had on the co-storytellers' lives? (As opposed to the problem-saturated stories.)

With this curiosity in mind, I hope to contribute to the little research that has been done in South Africa on autism spectrum disorders. It will provide an opportunity to document the narratives of people who have been influenced by a person with autism. In addition, I also hope to document the possible alternative stories about autism as opposed to the vast body of research consisting out of 'problem-saturated' stories. This will provide an opportunity for the co-narrators to voice their stories and experiences, as well as for me, the inquirer, to share the experiences and knowledge

that I have gained through living with a sister with autism. The study also aims to give Leyna a voice, because she cannot voice her opinions, feelings, and experiences as we are able to. Inevitably, to give her a voice will be difficult. However, it will be valuable even if we just touched on how she might be seeing the world – even if it is beyond our way of understanding her. In order to answer to my research curiosity, the storying process will require a paradigm that will enable the alternative stories to be told in a valid, ethical manner, i.e. through the narrative research lens.

Plan of inquiry

For the plan of inquiry, I will follow a narrative approach to inform my research. Following this school of thought, the inquirer wants to know how people perceive their realities. I would therefore want to understand the meaning of the co-storytellers' experience, i.e. how they view their reality. These meaning-making processes of the co-storytellers will then become written accounts of their experiences of interacting with Leyna. For this reason my research will consist of a qualitative research plan of inquiry. It is of importance to note that narrative research is referred to as a subcategory of qualitative research in the social sciences (Josselson, Lieblich & McAdams, 2003). The advantages of writing up narrative accounts are that they "enable readers to participate vicariously in other people's thoughts and emotions that are associated with events the readers would never directly experience in their own lives" (Thomas, 2003, p. 39). This connects with the purpose of the study, i.e. to show outsiders that there are also alternative, inspirational stories that people have to share about being personally involved in the life of a person with autism spectrum disorder. One needs a well-planned plan of inquiry to unlock these stories and ensure the validity of the study and ethical considerations that are involved when a narrative approach is used.

Overview of qualitative research

According to Merriam (1998, p. 5), qualitative research can be seen as "an umbrella concept covering several forms of inquiry that help us understand and explain the meaning of social phenomena with as little disruption of the natural setting as possible". Within this type of design, the inquirer is not looking for quantifiable

figures of data as is evident in quantitative, positivistic research designs. Rather, "such [qualitative] research takes a giant step away from parsing human experience into predefined 'variables' … Rather than forming hypotheses, the inquirer frames questions for exploration; in place of measurement are the challenges of deeply listening to others" (Josselson et al., 2003, p. 3). It views research through a postmodern lens as opposed to a positivistic, traditional one. I will elaborate on this approach in the next section.

Merriam (1998) mentions several characteristics of qualitative research that are fundamental when engaging in this type of study. As has been noted, "qualitative inquirers are interested in understanding the meaning people have constructed …" (p. 6). Other characteristics, specifically pertaining to the role of the inquirer, are that the inquirer becomes the person who does the fieldwork and gathers the stories. This means that there are no endless inventories or questionnaires involved to obtain data. This adds to its personal nature. Qualitative research can also be viewed as an inductive process rather than deductive one: "In contrast to deductive inquirers who hope to find data to match a theory, inductive inquirers hope to find a theory that explains their data" (Goetz & LeCompte, 1984, p. 4). Finally, Merriam (1998) emphasises the fact that qualitative research studies focus on bringing forth rich, descriptive accounts of the people that they study. Qualitative inquirers, then, search for the meaning that people attach to certain aspects of their lives – they search for the *essence* of personal accounts and experiences. Durrheim (1999, p. 43) summarises my reason for choosing a qualitative research approach quite well when he says the following: "If the research purpose is to study phenomena as they unfold in real-world situations, without manipulation, to study phenomena as interrelated wholes rather than split up into discreet predetermined variables, then an inductive, qualitative approach is required." It is important to remember that the personal, delicate nature of a qualitative study amounts to great responsibility that rests with the inquirer. As Winston Churchill (1943) said in his speech at Harvard University, "The price of greatness is responsibility." For this, then, to be a meaningful, contributing study to the field of qualitative research, I will have to keep my responsibilities in mind, especially because I am so closely involved.

According to Neuman (2000), four errors of personal experience need to be taken into account when doing qualitative research. The first error is that of *overgeneralization.* This happens when the inquirer has some ideas that he or she believes and then assumes that they apply to other situations too without asking the co-storyteller to elaborate on them. Secondly, *selective observation* occurs when you generalise from people or events that you take extra notice of. Another error is that of *premature closure.* This happens when the inquirer feels that he or she has all the answers and information that are needed and does not need to listen any longer or gather any more stories. Lastly, the *halo effect* means that "we over-generalise from what we interpret to be highly positive or prestigious. We give things or people we respect a halo, or a strong reputation" (Neuman, 2000, p. 5). These four errors particularly apply to my situation, for I am personally involved with all of my co-narrators. A study of this nature also evokes many emotions and experiences. For this reason I will make use of personal reflexivity throughout the study as a means to try to limit Neuman's four errors of personal experience in my own work.

Reflexivity can be seen as "one of the pillars of 'critical' qualitative research and relates to the degree of influence that the inquirer exerts, either intentionally or unintentionally, on the findings" (Jootun, McGhee & Marland, 2009, p. 42). That means that the inquirer actually recognises the fact that they are part of the study and the co-storytellers' life stories. Furthermore, Jootun et al. (2009, p. 42) state that "reflecting on the process of one's own research and trying to understand how one's own values and views may influence findings, adds credibility to the research and should be part of any method of qualitative inquiry". Jootun et al. (2009) argue that using reflexivity in their research improved their data reliability as well. They see the inquirer's role as being a prompter and a prober – someone who encourages the co-narrators' views of their experiences. By reflecting on the process throughout the study, I will therefore know my own thoughts, opinions, subjectivity, and judgements better and add more genuineness to the research voyage. I will also be able to see where I made mistakes and learn throughout this voyage – it will contribute to a deeper insight on the research process. In conclusion, one can say that the reflexive process "is an invaluable tool to promote unbiased, deep understanding of the phenomenon under study and how the issue of subjectivity can be turned into an

opportunity" (Jootun et al., 2009, p. 46). I see this as an opportunity for personal growth and understanding when working so closely with people.

The previous section looked at the most important characteristics of a qualitative research plan and the reason why I chose this specific plan of inquiry for my research voyage. It also emphasised the responsibility that lies on the inquirer when doing a study of such a personal nature, and showed how reflexivity can be used as a tool to improve the reliability of the stories gathered. The next section will focus on the narrative approach that falls under the umbrella term 'qualitative research'.

Research paradigm: Following a narrative approach

As mentioned earlier, narrative inquirers seek alternatives with the co-storyteller to narrate other preferred life stories. In order to do this, the inquirer needs to work from a paradigm that considers equal power relations as important and believes that the use of language (historically and culturally) influences the co-storyteller's meaning making and construction of identity. This is referred to as post-structuralism. It is, then, important to discuss the narrative paradigm[5] as a poststructuralist approach to research in order to understand the school of thought in which it is grounded.

According to Morkel (2008), narrative inquiry is based on various schools of thought and theories, such as postmodernism, social constructionism, post-structuralism, and feminism. All of these theories partly contribute to the paradigm from which a narrative inquirer works when working with his or her co-storytellers: "It is situated in the social constructionist, postmodern, post-structuralist discourse that challenges and forces a re-evaluation of humanism and traditional psychological and counselling discourses" (Besley, 2002, p. 125). Post-structuralism particularly informs and shapes narrative approaches, and a deeper understanding of this theory is needed to understand narrative thought when co-storytellers tell their life stories. In a review essay on books about postmodernism and qualitative research, Travers (2006, p. 267-268) states that "a new kind of qualitative research is desirable and necessary: one that celebrates inter-determinacy and constructionism through exposing the short-comings

[5] For the purposes of this research voyage, I used some narrative practices that were introduced to the therapy realm by Michael White and David Epston to inform my research (Morgan, 2000). Both approaches flowed out of the post-structuralist era.

of positivism as an epistemological position". This, of course, all relates to the use of a narrative paradigm that informed my research voyage.

To be able to grasp the concept of post-structuralism, one first needs to know what structuralism is and thus from where post-structuralist thought evolved (Thomas, 2002). According to Macey (2000), structuralist thought was one of the most influential movements in the twentieth century and came to the fore in the late 1950s to mid-1960s. Although a difficult concept to define, "the underlying assumption [of structuralism] was that there are fundamental, unchanging structures which govern everything from the cosmos to the behaviour of minute particles" (Thomas, 2002, p. 85). Structuralism can therefore be seen as an ideology of science, which means that it sought the "unification of the human sciences by applying a single methodology" (Macey, 2000, p. 365). These scientific methods influenced the diverse disciplines of "anthropology, literary criticism, psychoanalysis, Marxism, history, aesthetic theory and studies of popular culture" (Besley, 2002, p. 130). Evidently, the world of inquiry was also influenced, and structuralists "began to look for the underlying internal structures of people, families, societies, culture, language, etc." (Thomas, 2002, p.85).

Therefore, Structuralists assume that people can be studied in the same way that objects are studied, and try to apply these scientific laws to human beings (Thomas, 2002). Furthermore, they have a specific way of viewing identity, personhood, and power. They seek to classify individuals in terms of classes or types and value expert knowledge on the constructing of people's identities. They also believe that a person has a deeper identity that that seen on the surface and that only they (the experts) have the key to unlock this deep, hidden inner self. On the whole then, they try "to assign meaning to people's life stories by decoding the formulas that underlie their structure" (Freedman & Combs, n.d.).

In contrast, post-structuralism is not focused on science alone; "it challenges the overly optimistic and social scientific pretensions of structuralism" (Besley & Edwards, 2005, p. 278). It developed in France in the late 1960s, and was influenced by the work of Derrida, Baudrillard, Lyotard, Foucault and Deleuze (Macey, 2000). In short, post-structuralism "provides a critique of the human subject as rational, autonomous and self-transparent; a theoretical understanding of language and culture as linguistic and symbolic systems; and a belief in unconscious processes and in

hidden structures or socio-historical forces that order and govern our behaviour" (Besley & Edwards, 2005, p. 278). It sees people as the experts on their own lives and values local knowledge.

Another pivotal theoretical movement that developed from postmodernism is social constructionism. Although it is a complex concept to define, it relates strongly with narrative practices and thus requires some attention. In her book, *Social Constructionism,* Burr (2003) explains that there is no objective meaning to reality and that all meaning is a human creation influenced by social and cultural factors. She states: "We are born into a world where the conceptual frameworks and categories by the people in our culture already exist" (Burr, 2003, p. 7). She also emphasises the importance of language, and states that it is not merely a way that people express themselves, but rather a construction of the world surrounding us when people are talking to each other.

Burr (1995, p. 8) explains the purpose of social constructionism in the following way:

> A major focus of social constructionism is to uncover the ways in which individuals and groups participate in the creation of their perceived social reality. It involves looking at the ways social phenomena are created, institutionalised, and made into tradition by humans. Socially constructed reality is seen as an ongoing, dynamic process; reality is reproduced by people acting on their interpretations and their knowledge of it.

It is important to keep this view in mind whilst doing and reading narrative research, as reality is seen as an ongoing creation, subjective to the meaning making of the storytellers.

Michel Foucault, a French theorist of post-structuralism, influenced narrative inquirers to "not only question the dominant assumptions underlying humanism and psychology, but also to address issues of meaning, subjectivity, power and ethics" (Besley, 2002, p. 125). He therefore also emphasised the use of language as an important instrument of power, which influences people's constructions of identity (Morkel, 2008). Based on his work and the theory of social constructionism, narrative inquirers believe that "people have the power to construct meaningful lives through

the stories they enact, tell and remember with one another" (Freedman & Combs, n.d.).

In summary, one can say that post-structuralism sees meaning making and the forming of identity as a shared process between the co-storyteller and other significant role-players in their lives (including the inquirer), but also as an ongoing process of recreation (Thomas, 2002). In other words, people's identities are constantly being socially crafted by several power structures in their worlds, and not something internally fabricated. However, by using reciprocal language and telling stories, we do have the power to construct new, deeper meanings to our realities through our interactions with one another. In this regard Burr (2003, p. 9) says, "Knowledge is therefore seen not as something that a person has or doesn't have, but as something that people do together." It is clearly important to overview the narrative principles with which the inquirer enters the discussions.

Narrative principles

> *"Courage is what it takes to stand up and speak; courage is also what it takes to sit down and listen" – Winston Churchill (Moncur, 1994-2007).*

As mentioned previously, in this narrative research study I used some of the principles of narrative therapy to encourage stories. According to Alice Morgan, there are two principles that are significantly important in the relationship between the inquirer and the co-storyteller: "always maintaining a stance of *curiosity*, and always asking *questions* to which you genuinely do not know the answers" (Morgan, 2000, p. 2). It is important to keep this in mind in research where the inquirer is personally involved, because the inquirer can never assume that he or she is the expert on the co-storyteller's identity. Once again, one can see that power relations are of extreme importance.

Therefore, another principle that I would like to mention is that of *collaboration*. In brief again, narrative research focuses on the co-construction of meaning: "Narrative conversations are interactive and always in collaboration with the people consulting the inquirer" (Morgan, 2000, p. 3). Moreover, "Narrative research is different ... It requires that the interviewer keep her research aims and personal interests in mind,

while leaving enough space for the conversation to develop into a meaningful narrative" (Josselson & Lieblich, 2003, p. 269-270). This has vast implications for the types of questions that we as inquirers ask our co-narrators.

When asking questions or gathering stories in the narrative approach, the inquirer has specific intentions when eliciting stories from the co-storyteller (Freedman & Combs, n.d.). Furthermore, some of the most important intentions, specifically pertaining to narrative research, are asking questions that "generate experience, offer the possibility of different perspectives, contribute to a sense of collaboration and honouring of the person's knowledge, support shared meaning making, and finally asking questions that contribute to shrinking problem stories and focus on growing preferred stories" (Freedman & Combs, 2008). With these narrative intentions as foundation, I formulated certain guiding questions for the discussions with my co-storytellers (see Addendum A). It should be noted that asking these types of questions alone would not necessarily bring forth the alternative, preferred stories that I want to write up. It also depends on how I listen to these stories.

Another important principle of narrative is that of *double listening*. Freedman and Combs (2008, p. 2) refer to it as listening to the "absent but implicit". With this they mean that "[t]he meaning we (as inquirers or as co-narrators) make of any experience comes from contrasting it with some other experience or experiences". It goes without saying that within any research relationship it is important to listen attentively to what your co-storyteller is telling you. Nevertheless, narrative inquirers take this even one step further. They listen for "those experiences that allow us to discern the things we have been focusing on" (Freedman & Combs, n.d.). We therefore listen to that which the co-storyteller is not directly telling us – for 'unique outcomes' – i.e. stories or experiences that contrast the problem-saturated story (Morgan, 2000, p. 52). We (collaboratively) then use these unique outcomes to story an alternative one – one that tells of all the events in our lives that did not focus on problems alone. This is what working narratively is all about.

The research voyage was based on the above principles, and will be discussed in further detail in the next section.

The modes of inquiry

This section will give a short overview of the modes of inquiry that were used during this study. Part 3 will further explore the aspects that follow.

Finding the co-storytellers

The focus of the study was on the narrative experiences of five people who have been directly involved in caring for Leyna over the years, including my own interwoven story, in order to share the true stories about the influence of Leyna's presence in our lives. The scope of the research was therefore narrow, as the aim of the study was not to generalise, but to reveal the life stories of a specific group.

This study was based on a purposive sample, because this sample was chosen "on the basis of what the inquirer considers to be typical units" and "the strategy [was] to select units that [were] judged to be the most common in the population under investigation" (Bless & Higson-Smith, 2000, p. 92). The sample consisted of four people who had been closely involved in Leyna's life for a period of longer than three years. This includes both her parents, one of her siblings, her caregiver at home and her teacher at her old school. They were all involved in the storying process. In addition, my personal experience of having a sister with autism spectrum disorder was storied throughout the study, forming the main storyline.

Gathering the stories

I made use of individual discussions, speaking to four people who had been touched by Leyna's presence in their lives. Narrative practices (such as respectful curiosity, the deconstruction of the problem, discovering unique outcomes and thickening the alternative story) were used to gather information that could potentially answer my research curiosity. The stories gathered during these discussions were recorded on a digital voice recorder and were transcribed fully afterwards. I needed to have several discussions with each co-storyteller, depending on the themes that evolved throughout the interviewing process. I also inserted a narrative account throughout the thesis of my own experiences of having a sister with autism, as well as my reflections on the research process.

My own story, which was interwoven with the other stories, therefore played a role in the research. Prinsloo (2004) gives the following reason for including her own and others' voice(s) in the story: "As inquirers writing narratively, we have become to understand part of the complexity as a problem in multiple I's. We become plurivocal … yet living the narrative inquiry process, we are one person" (Clandinin & Conelly, 2000, p. 9). The narrative paradigm also acknowledges and respects human experience, and emphasises the impact of personal and social context on one's life. It is for this reason that Prinsloo (2004, p. 9) states that she cannot remove herself and her own story from the research study. Dudley-Marling (1996, p. 36) emphasizes the genuineness of such an approach in the following way:

> Hiding the 'I' is a pretence of a fraud that forces me to hide my passion, to deny who I am and to pretend that my words are separate from me. Acknowledging the 'I' allows me to reveal myself and my feelings.

I understood that adding my own voice would be beneficial to the research process, because inquirers must be willing to explore their own stories and gain a greater understanding of themselves with the help of people that are the closest to them – the people that they trust (Monk, Winslade, Crocket & Epston, 1997). In summary, I want to state that I wanted all the voices of the people in my sister's life to be heard and to be storied, because voices come together and emerge, entangle, they enmesh and they separate. We share the experiences of (dis)ability and all its connotations (Kliewer, 1998). I wanted to offer others the opportunity to see (dis)ability through an alternative lens. Prinsloo (2004) also tells us that we need many stories in this diverse world that we live in. We need powerful, accessible stories from the heart. In this way, we will be able to learn about each others' stories with understanding and be able to influence our own stories. I hope that, through doing this study, these stories will change others' stories about autism.

Making meaning of the stories

The stories gathered were transcribed and I attempted to make meaning from them through thematic analysis. To contribute to the validity of the stories, triangulation was used and more than one co-storyteller was involved in the study. Thereafter, I documented the stories and alternative accounts that were eminent throughout the discussions.

Ethical considerations

Several ethical issues needed to be considered in planning this research voyage. The main ethical consideration was the protection of my sister's well-being and needs. The study focused on the narrating of alternative stories that would be empowering and enlightening for us as a family, the co-narrators and especially for my sister. With this as the guiding purpose throughout the storying process, it was envisaged that risks and discomforts would be minimised. Ethical clearance was also obtained in order to assure that Leyna's interests would be constantly considered. Part 3 will discuss these considerations in more detail.

Reflections on planning my voyage of discovery

In Part 1 above, I started out by giving a description of my research study as a voyage of discovery. I explained my interest in this specific study, my personal relationship to the girl with autism spectrum disorder, as well as the knowledge gap that exists in South Africa. I also explained the reason behind my curiosity in this research. I positioned myself within a qualitative research design, as an inquirer who would follow the narrative paradigm to inform my study. I also explored the concept of reflexivity and its meaning for me as a narrative inquirer and co-storyteller. I touched on the most important principles of a narrative approach and once again realised the importance of *shared* meaning making.

In Part 2 of the research voyage, I delve more deeply into the literature to find out what stories exist about autism and to determine how that will impact on the stories that we tell.

In Part 3 I focus more intensively on the plan of inquiry that was intended to set this voyage of discovery in motion.

Part 4 reveals the themes of the stories told on this voyage, and in Part 5 I share my reflections on the process and suggest ideas for possible future research opportunities in the field of autism.

Part 2

The literature review: A closer look at existing stories

> *"Strange is our situation here upon earth. Each of us comes for a short visit, not knowing why, yet sometimes seeming to divine a purpose. From the standpoint of daily life, there is one thing we do know: that we are here for the sake of others ... above all, for those upon whose smile and well-being our own happiness depends, and also for the countless unknown souls with whose fate we are connected by a bond of sympathy. Many times a day we realise how much of our own outer and inner life is built upon the labours of other human beings, and how earnestly we must exert ourselves in order to give in return as much as we have received and are still receiving."*
>
> *Einstein ("Albert Einstein Quotes", 1999-2009)*

I see Leyna as this gift to my life, and I do not know how to repay her for the amount of personal growth that I have received. When I think about her, I do not think about all the times that I could not get through to her. Or how I struggle to understand what she wants. I do not think about the hurt that I feel when she is crying and I have no idea what she is experiencing. When I think of Leyna, I think about her smile. I think about her unconditional acceptance of me. I think of that kind of knowing that comes over me that I am here for a reason. I see her autism as a gift to my life – not always easy, but definitely with a purpose. The global definition of autism spectrum disorder is, unfortunately, more complicated than this.

In this part I will focus on defining the complex concept of autism within the following theoretical paradigms: the medical deficit and the bio-ecological paradigm. I will then discuss the impact of these models on how the characteristics of autism are viewed. Furthermore, I will illustrate why a post-structural paradigm is needed to define autism. Thereafter I will focus on the consequences of these models on studies about autism and the knowledge gap that exists specifically within South African studies. I will use this as a motivation as to why I chose to go on this specific research voyage.

The medical deficit model

As was mentioned in Part 1, little research has been done on the alternative stories that people experience about having a person with autism in their lives. The focus has primarily been on the problem-saturated stories that focus on stories about family stressors, pain and suffering. This negative focus has, unfortunately, been part of a global discourse about autism, and disability in general, for a long time. For decades parents and people with disabilities have been advocating for their voices to be heard by society.

At an international level, this broader movement towards inclusion started with parents and churches who established asylums as sanctuaries for children with disabilities (Du Toit, 1996). Later in the twentieth century, this led to special classifications of children with disabilities and these children were placed in 'special' schools with the aim of removing or alleviating " the particular deficiencies of such children" (Du Toit, 1996, p. 6). This view, namely that the problem lies within the child and that the child should be excluded because of "a disability that is thought to be a natural and irremediable characteristic of the person" (Naicker, 1999, p. 12), is called the medical deficit paradigm. A paradigm can be described as a certain type of lens through which society looks to understand a certain phenomenon, such as disability. In other words, paradigms are "alternative ways of thinking … about human nature" (Swart & Pettipher, 2005, p. 4). This paradigm meant that the child with the disability had to fit in with the world, and not vice versa. This is, unfortunately, frequently still the case today.

In the late 1960s one of the ways in which Western society tried to 'normalise' these children with 'special needs', was that they started to move away from the medical paradigm (Swart & Pettipher, 2005). The concept of 'special needs' suggests that there is something wrong with the child and that the child should change to fit in with 'normal' developing peer groups. The concept of integration was another step forward toward inclusion. The purpose of integration was "to ensure that learners with disabilities are assigned equal membership in the community … It aims to maximise the social interactions between the 'disabled' and the 'non-disabled'" (Swart & Pettipher, 2005, p. 7). However, this only resulted in the 'special' services moving to the school. Learners were thus still excluded and segregated and "difference was still

being accentuated" (Engelbrecht, 1999, p. 8). This is another characteristic of the medical deficit paradigm.

One of the global milestones of challenging the within-child paradigm or medical discourse was attained at the World Conference on Special Needs Education 1994 in Salamanca, Spain. The conference focused especially on the "development of an inclusive philosophy in schools" (Engelbrecht, 1999, p. 9). The overall purpose of this conference was "to further the objective of education as a fundamental human right by paying attention to the fundamental policy shifts necessary for the development of inclusive education" (Swart & Pettipher, 2005, p. 8). This statement led to global educational reform that indicated a move from the medical deficit model to the bio-ecological paradigm, which recognized the change of the system to respond to the child and his or her rights. Education for all, which was the key outcome, was one of the influences on South Africa's educational transformation.

The bio-ecological paradigm

Within the previous section, much emphasis was placed on the importance of context. The shift from the medical deficit paradigm towards the bio-ecological framework was discussed. It was also mentioned that the systems were now challenged to change in support of the child, and not that the child had to fit in with the system. Consequently, when discussing context, one cannot ignore the complexity of the relationships between different individuals and their surrounding systems, especially with the big paradigm shift that occurred concerning inclusion. This paradigm shift required a change in all of the different systems.

Bronfenbrenner, who was interested in child development, constructed the ecological systems theory or bio-ecological framework to understand this "complexity of the influences, interactions and interrelationships between the individual learner and multiple other systems that are connected to the learner" (Swart & Pettipher, 2005, p. 9). He developed "a complex but powerful ecological model involving different levels of system in the social context" (Donald, Lazarus & Lolwana, 2002, p. 51) to underlie the complexity of any disability and hence inclusion. The bio-ecological theory is a meta-approach to understanding disability – i.e. a theory about theories. Hence, it is of interest to deconstruct the concept bio-ecological theory, to gain a deeper

understanding of its underlying philosophies, and the way in which these are functional systems to explain autism.

The prefix ‘bio’ refers to the *intra*-related systems that interact with each other and make up the individual as a system. This includes “physical, emotional, biological and psychological” systems (Swart & Pettipher, 2005, p. 10). The word ‘ecological’ refers to the *inter*-related systems that interact between the individual and his or her world. This relates to the theory of ecology which “is based on the interdependence and relationships between different organisms and their physical environment. Every part is as important as another in sustaining the cycles of life … which together ensure the survival of the whole system” (Donald et al., 2002, p. 45). By putting the ‘bio’ and ‘ecological’ components together then, a theory was formed about the complexity of individuals who have to interact with themselves and other systems every day and through these influences turn out to be included or not. In other words, the contexts in which individuals find themselves shape their realities. This connects with the social constructionism upon which narrative research is based.

The context in which societies, cultures, people, communities and individuals find themselves is an intricate part of inclusion, because it will determine how challenges such as autism will be viewed or addressed. The context is broken up into parts or “environmental systems [including] the microsystem, the mesosystem, the exosystem and the macrosystem” (Swart & Pettipher, 2005, p. 10). These contexts all interact with each other over time – the chronosystem.

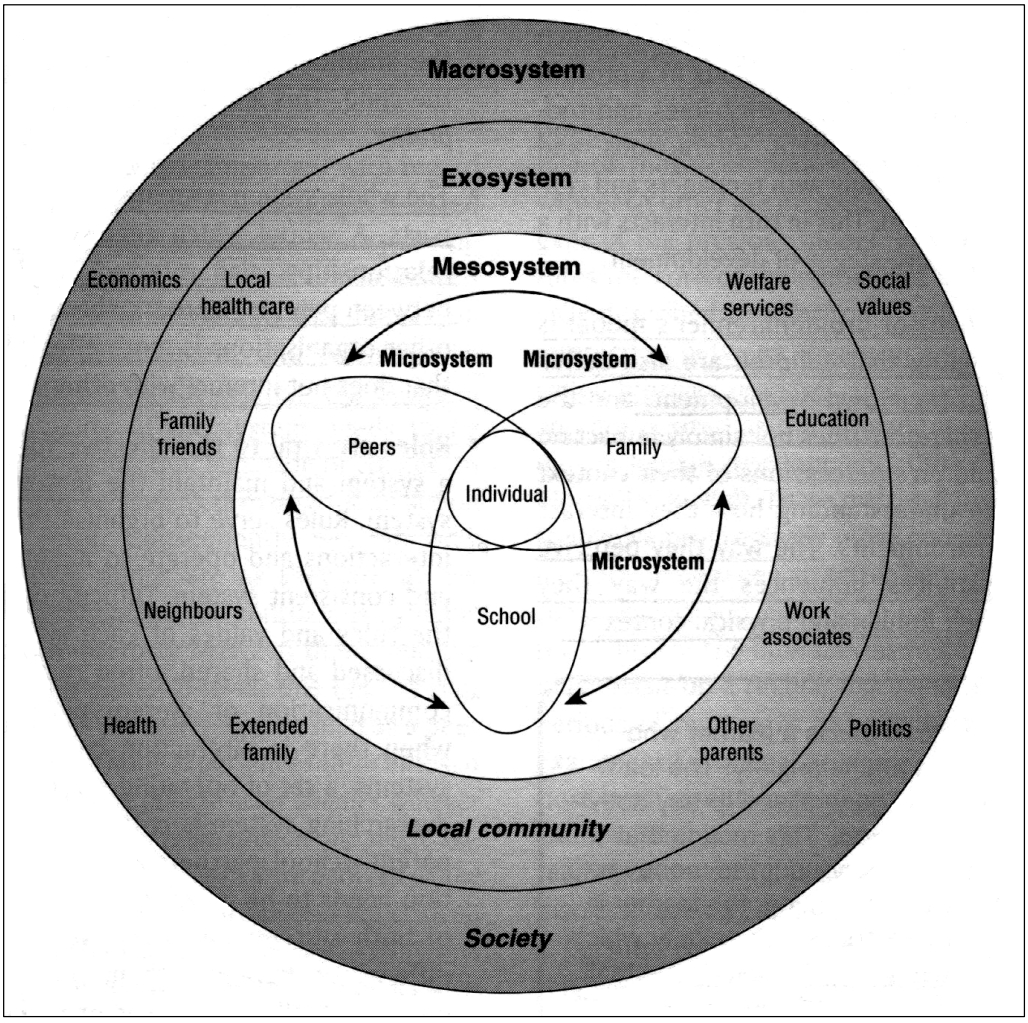

Figure 2.1: The Bio-ecological model layout (Swart & Pettipher, 2005, p. 11)

Figure 2.1 above is an illustration of these different interrelated, interacting contexts. Although the figure presented linearly and simplistically, it is important to understand that the inclusion of autism is a multi-directional, compound process and "what happens in one system affects and is affected by other systems. In other words, relationships among causes are reciprocal" (Swart & Pettipher, 2005, p. 10). This is also referred to as "circular causality" (Swart & Pettipher, 2005, p. 12).

On the whole then, the bio-ecological theory or model is one framework (part of a meta-approach) to better understand the inclusion of autism, especially within specific contexts. These contexts, whether they are intra- or inter-related, are in constant

interaction with one another. A change in the one context will have an effect on other contexts. It is therefore clearly a complex, reciprocal process.

This reciprocal process can be illustrated by elaborating on the concept 'barrier to learning'. A barrier to learning can be defined as anything that divides a problem from the individual, rather than the problem being in the individual self. It refers to any barrier that may prevent a child from reaching his or her full potential, and consequently to become fully included within society. According to Donald et al. (2002), barriers to learning are situated on a continuum that ranges from internal to external. These barriers range from the individual student as microsystem (internal) to the whole macro social system (see Figure 2.1). However, it is important to be aware that these barriers are situated in between the interactions within the different systems, and not in the systems themselves (Donald et al., 2002, p. 56-57). This is also referred to as the "systems change approach, which locates the barriers on different levels of the system" (Swart, 2004, p. 237). This paradigm therefore helps one to view the barriers as not within the person with autism self, but rather as a complex set of factors influencing each other and that creates barriers between the different systems.

On the whole then, although I find this approach useful to explain the definition of autism, the bio-ecological paradigm is still limiting. It tries to break up people, places, events and experiences into set structures that can be explained and defined. As mentioned in Part 1, this kind of paradigm forms part of the structuralist era. One can see that what is necessary is another lens that captures all the complexities of life and experience; that sees reality as something that is constantly being reproduced by the stories that we tell ourselves and others (Burr, 1995; Freedman & Combs, 2008). I therefore envisage a post-structuralist, narrative lens from which to view autism. Through this lens reality would be seen as a process that is being created all the time.

The lens on autism spectrum disorder

According to Sarah Allred (2009), Asperger's syndrome – another condition that falls into the category of autism spectrum disorders – is also mainly defined by two distinct discourses. On the one hand, there is the medical approach (as discussed in the previous section) that "classifies Asperger's Syndrome as a mental disorder" (Allred, 2009, p. 343). On the other hand, there are "accounts [that] provide further support for

reframing Asperger's Syndrome as a socially constructed human difference rather than pathology" (Allred, 2009, p. 343). This, again, connects with the narrative principle of social constructionism as discussed in Part 1. These discourses are evident in the literature on autism, and I will explain autism in the light of these discourses interchangeably throughout this section.

The *Diagnostic and Statistical Manual of Mental Disorders* (DSM IV-TR) classifies the broader spectrum of autism as Pervasive Developmental disorders. This manual is used by professionals across the globe with the main purpose of diagnosing children with 'disorders'. These diagnoses are "characterised by severe and pervasive impairment in several areas of development: reciprocal social interaction skills, communication skills, or the presence of stereotyped behaviour, interests, and activities" (American Psychiatric Association, 2000, p. 69). These characteristics will be discussed in the next section. It is evident that in the DSM-IV-TR the medical deficit model is still used to categorise and diagnose. Words such as 'severe impairment', 'abnormal', 'disturbance' and 'disorder' are used interchangeably (American Psychiatric Association, 2000). The World Health Organisation's international coding system, namely the ICD-10 codes, is no different from the American Psychiatric Association in their discourse of medicalisation and classification. Words such as 'abnormalities', 'impaired development', and 'areas of psychopathology' are used to define autism ("World Health Organisation", 2009, p. 198). Leyna's 'medical' diagnosis was that she had Pervasive Developmental disorder, with severe mental handicap, when she was three years old. This was after she had reached most of her developmental milestones late and had very limited speech. I do not remember much of this, because I was still very young. I do know that it must have been devastating news to my parents. In this regard, Sarah Cruce, an adult woman with autism, states the following in her book: "Autism is typically relegated by mainstream healthcare to the world of disease and is commonly misdiagnosed as a problematic disorder" (Cruce, 2008, p. 1). These definitions and diagnostic criteria of autism seem to have set the discourse for the global community. It should be noted that, despite this medicalisation of autism, the diagnostic criteria mentioned above has contributed to autism awareness, as it is more recognisable and more diagnosed than in the past.

Ferguson (2002, p. 124) states that "[a] family's interpretation of the meaning of disability cannot help but reflect to some degree the larger context of social attitudes and historical realities within which that interpretation emerges". Take, for instance, the influence of the media on our everyday realities. The medical discourse in the following media statement is evident: "With one in 166 children being diagnosed with autism, it can no longer be called rare. *We have an epidemic on our hands.* Every 16 minutes, another child is diagnosed with autism" (Julie Krasnow, *Indianapolis Star*, cited in Stillman, 2008, p. 33). There are a many websites that also define autism within the medical deficit paradigm. Some of the core phrases of these include "Defeat autism now," "autism is reversible" and it needs to be "treated and cured" (Autism Research Institute, 2008-2009). Autism is presented as a "puzzling, disturbing severe developmental disorder". The authors of these websites claim to "mentor thousands of families in recovering their children" (McCarthy, n.d.). It is evident that people with autism are not accepted for their uniqueness or difference. For this reason, Stillman (2008, p. 20) rightly states that "there are indeed people who consider individuals with autism, Down's syndrome, mental retardation, and other developmental differences, society's 'throw aways'". It is unfortunately still a reality that even in these postmodern times, children are seen as 'suffering' from autism. The consequences of this worldview are ghastly: "Screening out autism would breed a fear that anyone who is different in any way will not be accepted. Screening for autism would create a society where only perfection is valued" (Simone Aspis, parliamentary and campaigns worker for the British Council of Disabled People, quoted in Stillman, 2008, p. 19). And that has (regrettably) become our reality – perfection has become an intricate value that people strive towards.

Is it not interesting that the neuro-typical members of society try to hang a label on everything if it is not 'perfect'? Stillman (2008, p. 42) comments on society's need to explain, understand and manage everything: "autism is an industry … there are those who profit handsomely from scientific research-based methods, treatments, and programs that purport effectiveness as 'clinically-proven' to remediate … recover … *cure* autism".. As soon as something is different and cannot be placed in a certain category, then it is abnormal. Then our neuro-typical society members decide that a person must be 'suffering' from it, because it is just too different. It is unfortunate then that no one asks the persons with autism how they experience it, because they

have a 'social impairment' and will not be able to give you a scientifically valid answer. As Daria (2008, p. 90) points out, "people who cannot do what the majority can are labelled, at best, learning disabled, or, at worse, retarded". Stillman (2008, p. 45) comments that "[a] few [people] glean information to develop best practices from the experts themselves, the very persons who experience the autism".

It is evident that this discourse has a lot of power regarding how autism is perceived. In Part 1 I mentioned that Foucault emphasized the use of language as an important instrument of power, which influences people's constructions of identity (Besley, 2002). If one then looks at the construction of identity in people with autism, one sees that their identities have been constructed for them by the dominant discourse of society. Freedman and Combs (1996, p. 39) state that "people tend to become 'docile bodies' under 'the (internalised) gaze' of those who control the discourses of power in our culture". However, these 'docile bodies' are starting to rise and give voice and understanding to those who struggle to understand autism.

Contrasting the medical deficit paradigm, autism advocates, family members and (other) professionals are starting to view the concept of a 'disorder' differently. Harmon (2004) contends that this new view is "rooted in the view of autism as an alternative form of brain wiring, with its own benefits and drawbacks, rather than a devastating disorder in need of curing". Within the bio-ecological paradigm, a person who is diagnosed with autism spectrum disorder is not defined as having the 'problem' of autism. The person is firstly seen as a person and not as the problem itself. Autism is not a 'problem' that the person is 'suffering' from. Sigourney Weaver (cited in Stillman, 2008, p. 17) holds the following view of autism:

> I think we have to begin to see it as a gift. We may not understand what it is there for, but if you are in the presence of someone with autism you learn so much. You learn how to play, you learn how to see things, you learn how to experience things and how jarring the world is.

In contrast to the websites that advocate a cure for autism, there are also those that accept it as a difference. The Autism Acceptance Project (TAAP) is one of these websites ("The Autism Acceptance Project", n.d.). They do not see autism as a 'tragic epidemic'. Rather, they are tapping into human potential and dignity. They "work to

promote acceptance of and accommodations for autistic people in society" ("The Autism Acceptance Project", n.d.). Another example is the South African website called The Wallpapering Society. They are a group of people with Asperger's syndrome who advocate awareness and understanding by writing their blogs on this website ("The Wallpapering Society", n.d.). In his article "Don't mourn for us" Jim Sinclair, another autism advocate, describes the message being conveyed to a person with autism when their parents do not accept them for who they are. He asks that we (neuro-typical beings) look at autism from a person with autism's perspective (Sinclair, 1993, p. 1):

> Autism isn't something a person *has,* or a 'shell' that a person is trapped inside. There's no normal child hidden behind the autism. Autism is a way of being ... It is not possible to separate the autism from the person – and if it were possible, the person you'd have left would not be the same person you started with.

Maybe we are afraid of difference because we do not understand it. Miller (2006, p. 187) explains that it has always been this way: "how we will always want to control what we do not understand." If this is the case, then I will be brave enough to ask whether it is not we who need to change our stance towards difference, and embrace it rather than trying to cure it.

I turn to the bio-ecological theory once again to shed some light on my confusion. Within this paradigm, the barrier or 'problem' exists between different systems, rather than placing the problem within the person with autism. Miller (2006, p. 95) emphasizes that "[n]o matter how autistic they were or what their level of functioning was, the autism never masked the individual character and nature of each child". Moreover, within post-structuralist theory, identity is seen as something that is socially constructed, meaning that society needs to reconstruct its view on autism or, in narrative terms, recognize the alternative stories that exist in autism.

There is clearly no one specific reason only for including a person with autism in society. For example, on the macro level it could be the fact that there is little awareness in South Africa about what autism is, or the influence of the global discourse of disease that control people's views and opinions of autism. Or on a meso level, it could be the parents' struggle to accept that their child is different. Or it could

be the school environment that does not accommodate the learner with autism and his/her needs. Evidently, it is rather a complex, intertwined set of events that interrelate with each other. In short, it is substantial to understand that this complex process of inclusion has a great influence on how a person with autism's (and consequently other systems') beliefs, values, norms and evidently identity, are shaped and understood within our global society. Even so, I believe that "Nothing and *no one* was without purpose for being – even, or *especially*, those with different ways of being" (Stillman, 2008, p. 30).

After discussing the definition of autism from these discourses, I agree with Dasha the cat (from the book *Dasha's Journal*) when she says: "So far, my conclusion is that autism (like any other condition, including 'non-autism') may have both abilities and deficits" (Daria, 2008, p. 27). Let us have a closer look at the characteristics of autism.

Autism and the areas of 'impairment'

The DSM-IV-TR describes a person with autism to have "severe" and "pervasive" impairments within the following areas: "reciprocal social interaction skills, communication skills, or the presence of stereotyped behaviour, interests, and activities" (American Psychiatric Association, 2000, p. 69). For this reason, autism is often referred to as "The Triad of Impairment" (Koudstaal, 2005, p. 308). Other associated 'core deficits' of autism that are often described are "sensory and perceptual impairments" and "cognitive deficits" (Mash & Wolfe, 2005, pp. 294-295). These will be discussed critically in the next section by looking at each area separately.

Social relatedness

The first part of the triad of impairment is social relatedness. Mash and Wolfe (2005, p. 288) state that children with autism "experience profound difficulties in relating to other people" and their "social expressiveness and sensitivity to social cues are limited, and little sharing of experiences ... takes place". Dasha the cat, however, reframes the social relatedness of people with autism by comparing them with giraffes. She says that people used to think that giraffes also did not form friendships

and engage in relationships because of their different ways of interacting with each other. However, people just made the wrong assumptions about them, and they are in fact social creatures. The same goes for people with autism – just because their social interaction is different, it does not mean it does not exist (Daria, 2008). This is also true for Leyna. Although she has her times when she does not want you to bother her, she will mostly seek out your company as soon as you enter the house. Then she will walk in a route from person to person in the household, just to make sure that she does not miss anything exciting. I want to reiterate emphatically that their social relatedness is there, it is just different from the neuro-typical way of interacting. The same goes for communication.

Communication difficulties

The second part of the triad is communication difficulties. (Mash and Wolfe, 2005, p. 290) contend that "[c]hildren with autism display serious abnormalities in communication and language that appear early in childhood and persist". My sister said her first word when she was only nine months old. She picked up her play telephone and said "Hello". After that she did not say much. Her speech development was delayed, and even now, at the age of 19, she uses a limited vocabulary to communicate with us. This, however, does not mean that she does not have communicative intent. Communication in autism is happening all the time. The language that they speak is just different from ours and they have their own systems of communicating (Daria, 2008). Nevertheless, people with autism are often labelled as having this 'impairment' – one of the essential characteristics of autism.

An important aspect of people with autism that we need to remember is that they are very closely attuned to their sensory worlds, and this has an impact on how they communicate with others. Daria (2008, p. 107) points out that "[t]hey learn their language(s) through interaction with objects and other humans on the sensory level". This will be further discussed in the section on sensory integration. We should remember that just because their communication is different from that of the neuro-typical person, does not mean that we can force a person with autism to communicate with us using our means of communication that is primarily language-based. Perhaps our forceful attempts and lack of trying to understand autism from their perspective are the reasons that they exhibit 'problem' behaviours. Maybe it is their way of telling

us that we should stop changing them, and start accepting them. Let us take a closer look at these behavioural challenges.

Behavioural aspects

The third part of the triad is referred to as repetitive behaviours and interests. This includes, for instance, a fascination with a certain topic, repetitive body movements or stereotyped body movements, such as finger wriggling, rocking, flapping or spinning. It is difficult for a neuro-typical person to understand these behaviours, and several theories exist that try to explain them. However, this type of behaviour differs from child to child (Mash & Wolfe, 2005, p. 292). Furthermore, according to Daria (2008, p. 133) "[s]ome non-autistic humans include in this category any behaviour that is different from the norm". Again, the difference is emphasized.

In contrast, Daria (2008, p. 133) states that "[t]his isn't fair because some behaviour is absolutely *normal* autistic behaviours if you take into account their way of processing information and acting on it". Self-advocate Brian Henson remarked that "[p]arents and professionals who constantly tell children how they ought to behave suffer from 'oughtism'" (quoted in Stillman, 2008, p. 42). Although his statement is comical, it also contains a hint of truth. How much do we accept these children for who they are and how much do we try to change them into 'better, normal' human beings? Consider this following quote: "He [the child with autism] wants to be with others, while being himself, processing information and responding to the world in his own unique way" (Daria, 2008, p.146). In other words, people with autism want to be part of our world, but we tend to bombard them with rules and expectations, all the while just making the world an even more daunting place than what it already is for them. Miller (2006, p. 88) emphasizes that "[t]heir obsessive patterns of behaviour are a safe recourse when life becomes even vaguely challenging ... They need a constant, loving and stable support system." In the next little section I will try to explain how people with autism experience the world through their senses.

Sensory integration

Mash and Wolfe (2005, p. 294) state that "[m]any sights, sounds, smells or textures that most children find normal, can be confusing and even painful to children with autism". They experience, among other things, "over-sensitivities or under-sensitivities to certain stimuli, over-selective and impaired shifting of attention to sensory input, and impairments in mixing across sensory modalities" (Mash & Wolfe,

2005, p. 294). My sister is still terrified of any object that makes a loud noise, for instance a lawnmower, a power drill, or a vacuum cleaner. When she was younger she used to cry and scream about the sound of a lawnmower that was at least a block away. She now allows you to blow her hair dry with a hairdryer, and will not scream at the sound of a lawnmower any more. She will come and tell you, though, in her own way, "Scared of lawnmower! Scared of lawnmower!"

It is important for the neuro-typical person to keep the sensory sensitivities of people with autism in mind, especially because we do not have such a delicate sensory function. We need to see and imagine the world from their perspective, and help them to develop coping strategies with these painful sensitivities (Daria, 2008). If we start doing this, I think our perspective on autism will change profoundly, and a deeper understanding for each other will develop. For the same reason Miller (2006, p. 203) asks, "But again and again the philosophical questions arise: which world is better? Do we have the right to dictate that these children join our world, and on our terms, as far as possible?" I think we could both learn a lot from each other's worlds.

Let us look now at the emotional aspect of autism.

Emotion regulation

The concept of emotion regulation refers to "the processes by which emotional arousal is redirected, controlled, or modified to facilitate adaptive functioning, and refers to the balance maintained among positive, negative and neutral mood states" (Kopp, 1992, cited in Mash & Wolfe, 2005, p. 242). People with autism are often said to struggle with this – they are either lacking in emotions or being overly emotional (Daria, 2008). I think we tread on dangerous terrain when we make claims such as these, because we do not and cannot comprehend wholly what is going on in the mind and heart of a person with autism. Nevertheless, those of us who know a person with autism know that they experience feelings just as we do. I think this is the hardest part for me when it comes to my sister, because we do not know what is going on in her mind. According to Daria (2008, p. 128), "[t]he most common emotions (because they are most 'visible') in autism seem to be feelings of 'not belonging,' fear, stress, anxiety, depression and anger". In my sister's case, I experience this is as very

poignant because I realize that these are most likely the feelings that she is going through.

Another question that is asked often is that of empathy: Can people with autism empathise with those around them? The ability or "development of an awareness of the mental states in themselves or others is referred to as Theory of Mind (ToM)" (Mash & Wolfe, 2005, p. 295). Whenever one of my family members cries, my sister will always start crying too. When I am going through a tough time, it is almost as if she can feel my sadness. Yes, people with autism can definitely show empathy: "Autistic humans express this feeling differently, but they are capable of loving unconditionally, deeply and truly" (Daria, 2008, p. 128). And this is what makes every difficult moment worth the while.

Intellectual impairment

The last difficulty of autism that I would like to discuss is that of intellectual impairment. According to Mash and Wolfe (2005) about 70% of children with autism are also diagnosed with mental retardation. However, it has been questioned if this is a fair statement to make, as shown by the following quote (Daria, 2008, pp. 41-42):

> It is another reason why I find it easy to sympathise with autistic humans; for many years their intelligence has been measured with IQ tests that are designed to measure the intelligence of non-autistics. The abilities of autistics, while 'invisible', are so unusual that no existing test can measure them. As autistic individuals have different information processing strategies and styles, they might struggle with tasks presented in a conventional non-autistic way.

As said in the foreword of this dissertation, my sister has been diagnosed with mental handicap as a co-morbid disorder to her autism. What baffles me about this, though, is how alert she is in working things out. One cannot hide anything from her, because she will always figure it out. I know I am not an expert on this terrain, but somehow I feel that there is more potential and intelligence there that we just have not been able to tap into.

This brings us to the end of this section. After this information about the definition of autism and its main characteristics, let us move on now to see what research has been

done on autism, what the current trends in research are, and how the existing research links to this research voyage.

The focus of autism research: Past and present considerations

The following and final section of this part will take a closer look at what aspects of autism research scientists and other professionals have been focusing on. As I went through the different research journals (*Autism: The International Journal of Research and Practice, Autism Research, Research in Autism Spectrum Disorders, Focus on Autism and Other Developmental Disabilities*) that are particularly devoted to autism spectrum disorders, my heart sank. Out of the three issues that have been published in 2009, only two of the studies were focused on the family's perspective (Sage Publications, 2009). I did not see one study that was devoted to getting a perspective from the voices of people with autism themselves. And I thought: We still have a long way to go for our world-renowned policy on inclusion, *Nothing about us without us*, to become practice (Charlton, 1998). Let us have a quick review of these studies about autism.

Research focusing on the aetiology and curing of autism

In the journal, *Research in autism spectrum disorders,* numerous current research studies on autism (from 2007 to 2009) are listed. In a particular study, Matson and LoVullo (2009) provide an overview of past and current trends in autism. They undertook this study mainly because "the field of autism is expanding at an exponential rate" and "new topics for study are forming and journals are emerging rapidly to handle the ever-increasing volume of publications" (p. 252). They reviewed over 16 000 peer reviewed journal articles on autism, dating from 1978 to 2008. Their findings concluded that "the number of studies published on autism continues to increase" (p. 252). Furthermore, "the bulk of the most recent research has been on basic causes and psychological processes; genetics, neurobiology and physiology, developmental course, aetiology, theory of mind, language and communication, and perception and cognition" (Matson & LoVullo, 2009, p. 256). It was unfortunate to find that there was not one category that focused on the quality of life of people with autism, or studies that have been done *together with* them, and not *on* them.

Moreover, this was also apparent at other research-based institutes such as The Autism Research Unit and the Autism Research Centre, where the focus has been primarily on cause, cure and intervention as well (University of Sunderland, n.d.). Although there has been a greater focus on autism there still seems to be a huge knowledge gap in this regard, as well as in the general worldwide literature.

Research on autism seems to be a global focus for the research community as its prevalence continues to increase. A study at Cambridge University found that potentially 1 in 64 children in the United Kingdom could be presenting with an autism, ranging from mild to severe, as there could be many children still undiagnosed with the condition. According to the *Telegraph,* "[t]he increase in the prevalence of autism is probably due to better recognition of the condition by both parents and doctors, wider diagnostic criteria and more diagnostic services" (Smith, 2009, para. 16). Furthermore, this global focus is evident in the fact that the President of the USA, Barack Obama, paid particular attention to autism in his health plan. I was amazed when I first heard that Obama had included support for autism on his list of priorities, because there is still so little awareness about autism. I never imagined that a president would include it in his medical to-do list for the country. Barack Obama ("Obama Biden", 2009, March) highlighted the following four aspects:

1. Increased funding for research, treatment, screenings, public awareness and support services for [people with] autism spectrum disorders

2. 'Life-long services' for people with autism spectrum disorders, as children and as adults

3. More funding for the 2006 Combating Autism Act, as well as improving state and federal autism programs

4. Universal screening for all infants for autism disorders, as well as re-screening for all 2-year-olds.

This was wonderful news, as creating awareness about autism is cardinal if we want people with autism to be included in society. Some of his aspirations for autism were unfortunately based on the medical deficit model – trying to find a cause and combating it as soon as possible. It is not that I am totally against finding a cause, but

I wonder if they are ever going to find one – they have been studying this since 1943 when Kanner coined the term 'autism' (Koudstaal, 2005). Should we not rather accept it and be grateful for having these special beings in our lives? The above section discussed the focus of autism research globally. In the next section, we will focus on autism research in South Africa.

In South Africa, the University of the Western Cape Faculty of Natural Sciences and the Department of Biotechnology have been focusing on a project which examines the genetics of autism in a South African population (Arieff, 2009). Furthermore, the following causal factors are still being investigated, as indicated by Koudstaal (2005, p. 317): "There may be several different biological causes that all lead to autism by affecting the same area of brain functioning ... thus at present a multi-factorial aetiology should be considered." Another study at the University of Cape Town is investigating Theory of Mind[6] (ToM) development in children with autism. The aims of their study are firstly to "[c]ompare the developmental trajectory of ToM in typically developing South African children ... with that of children from other countries" and secondly to "compare ToM ability in South African typically developing and autism children" (Roberts, Malcolm-Smith & Thomas, 2008, p. 1). Although limited information on autism research is available locally, this appears to be the main focus in South Africa at present. At this stage you may be wondering if there are any studies focusing on the alternative stories about living with a person with autism. Unfortunately, in South Africa to date there are no such studies. However, globally, there has been some focus on this aspect. This will be discussed in the next section.

Giving voice to the (so far) unheard

As seen in the previous section, there have not been many studies focusing on giving voice to people with autism or their next of kin. Ferguson (2002, p. 124) argues that "a family's reaction to having a child with a disability is embedded within a socio-historical context". More importantly, though, is the influence that the child with a disability has on the family despite being embedded in this rich context. This is

[6] Theory of mind refers to a person's capability of understanding the mental states of others, i.e. how other people think and feel (Koudstaal, 2005).

evident in the limited number of studies that have focused on families living with disability, as indicated by King et al. (2006, p. 353): “There have been few reports of the world views, values and priorities of families of children with autism ... despite the fact that family belief systems are considered to be among the most important factors affecting the adaptation and resilience of families”. All the studies that have been done on this aspect draw more or less the same conclusions about living with a person with a disability. They are very important to consider when shaping alternative stories about disability in our global community and need to be looked at closely.

In 2001, Sheila Merzer wrote an article, “Looking backward, looking ahead”, in which she reflected on her professional life of working with autism for more than 25 years. In her reflections she states that although parents struggle with the initial acceptance that their child has autism, their perceptions do change over time, and they accept it “as part of the richness of the human condition” (Merzer, 2001, p. 42). Furthermore, she expresses the different ways in which parents describe their children, such as “compassionate, kind, motivated, funny,” in comparison to the diagnostic characteristics of autism, such as “restricted” (Merzer, 2001, p. 44). This already starts to shape an alternative story about individuals with autism. Ferguson (2002, p. 129) adds to this when he states the following:

> There is increasing recognition and growing research [indicating] that a significant number of parents actually report numerous benefits and positive outcomes for their families associated with disabilities. These include coping skills (adaptability), family harmony (cohesiveness), spiritual growth or shared values, shared parenting roles, and communication.

In addition, Ferguson (2002) also recognizes the hardships and stressors that accompany a child with a disability. This adds to the soundness of his study, as he does not try to hide the fact that it is a difficult reality to live with a person who has a disability. Fleischmann (2004) conducted a similar study where he investigated the stories that parents of children with autism wrote on the Internet. He concludes: “One can find in these synopses an engaging description of the ‘positive essence’ of the children and stories about them told with gentle humour … [a]long with the difficulties they encountered, most of the parents also described experiencing joy and

contentment" (Fleischmann, 2004, p. 37). Furthermore, he quotes one of the parents in his study as saying: "It is [both] a challenge and a blessing" (p. 37).

Another study that focuses on the alternative stories about autism is reported in an article called "A qualitative investigation of changes in the belief systems of families of children with autism or down syndrome". In this article (King et al., 2006, p. 353) conclude by saying the following:

> Although parents may grapple with lost dreams, over time positive adaptations can occur in the form of changed world views concerning life and disability, and an appreciation of the positive contributions made by children to family members and society as a whole. Parents' experiences indicate the importance of hope and of seeing possibilities that lie ahead.

In addition, Myers, Mackintosh and Goin-Kochel (2009) conducted a study where they asked parents, via a questionnaire, how their child with autism had affected their own and their families' lives. They came to the conclusion that "[t]he mix of negative and positive themes is interpreted as a dialectical viewpoint of finding positive meaning to life even while acknowledging the stress and difficulties of having a child with autism" (p. 683). The encouraging themes that the parents reported included a new outlook on their lives and disability as a whole, a deepening of spirituality, positive emotions such as compassion, kindness and joy for their nearest, an appreciation of the little things in life and an overall enrichment of their lives (Meyers et al., 2009). Surely, if one looks at all of these heartening stories from the people who encounter individuals with autism every single day, this calls for more research studies on this topic.

Reflections on the existing stories about autism

This part gave a thorough review of the literature that exists to date on autism research studies, and also gave some suggestions for future studies in this field. It started with the paradigms in which our global discourses are embedded and proposed the movement towards a more inclusive, post-structuralist worldview. We then had a brief look at the definition of autism and the alternative ways of looking at it – i.e. not as a disorder, but as a difference. It became evident in this part that studies that have been done on autism have mainly been focusing on the aetiology and curing of autism. The

few studies that have been more inclusive of families' voices on autism, portrayed evidence for the existence of alternative stories when living with a person with autism. However, the fact that it is a difficult reality to live with a person with autism and that one does experience challenges was not ignored.

We have also seen that a great knowledge gap still exists with regard to the inclusion of the voices of people with disabilities. With this in mind, we will now go ahead to the next part of the research voyage, namely the details of my plan of inquiry to gather the alternative stories.

Part 3

Modes of inquiry to unravel the story

> *"As with any voyage of discovery to an unknown place, narrative research … must chart a plan for how one hopes to carry out the exploration, including the tools that will be carried to aid the work, how the voyage will be documented, and how it will later be understood and discussed."*
>
> *Josselson & Lieblich (2003, pp. 261-262)*

This part will accentuate the details of how I developed my plan of inquiry, and will focus specifically on the following aspects: how the co-storytellers were recruited, how the stories were gathered and told, how I made meaning of the stories, how stories were validated, and the ethical aspects of the voyage that were considered for this personal research voyage. I agree with Josselson and Lieblich's stance regarding the use of the term 'methodology': "In our work, we have dropped the term 'methodology,' which carries deep connotations of the traditional research paradigm, and prefer to speak of modes of inquiry" (2003, p. 261). This study, as has been noted in Part 1, was not conducted within the positivistic, quantitative paradigm, but as a qualitative design within a narrative approach. I quote Josselson and Lieblich (2003, p. 260) to explain why I chose this approach:

> The narrative inquirer eschews methodolatry in favour of doing what is necessary to capture the lived experience of people in terms of their own meaning-making … Without detailed stories drawn in some way from co-storytellers, stories that reveal the way in which people view and understand their lives, narrative study is impossible.

I chose these specific modes of inquiry to come closer to exploring my research curiosity. It is therefore useful to briefly review the research paradigm and plan of inquiry that was discussed in Part 1 to orientate ourselves toward the voyage.

An overview of the narrative lens

According to Eisner (1997, p. 262), "[v]irtually any careful, reflective, systematic study of phenomena undertaken to advance human understanding can count as a form

of research. It all depends on how that work is pursued". As was discussed in Part 1, I decided to pursue my work through the narrative lens. Narrative theory is based on the idea that we are born in a storied world, and that our lives are lived according to the making and exchanging of narratives (Murray, 2008). Furthermore, Denzin and Lincoln (1998, p. 12) state that "[a]ny gaze is always filtered through the lens of language, gender, social class, race, and ethnicity ... Subjects or individuals are seldom able to give full explanations of their actions or intentions; all they can offer are accounts, or stories, about what they did and why". Therefore, I decided on this paradigm because it would allow me to story these events, experiences, actions and intentions about my sister with autism spectrum disorder. The purpose of this, however, was not to story the problem-saturated stories, but rather the alternative stories that came about by knowing Leyna. The curiosity that guided my research voyage was linked to this purpose and prompted me to ask the following question –

> What are the alternative experiences or influences that the girl with autism had on the co-storytellers' lives? (As opposed to the problem-saturated stories.)

With this question in mind, I decided on the specific developed narrative approach that "focuses on the relationship between individuals' life stories and the quality of their lives, especially their psychosocial development ... This includes gathering extensive life stories" (Chase, 2005, p. 658). Chase (2005, p. 658) explains that within this narrative approach, the co-narrators "are likely to tell 'narratives of redemption,' that is, to construct negative events as having beneficial consequences". It is important to note that I do not see the existence of my sister as a 'negative event' in our lives, although there are challenges that come with autism. I would, then, rather rephrase Chase's words of 'negative events' to 'challenging events.' Nevertheless, I found that the narrative approach that he proposes fit best to answer my research curiosity that guided my research voyage. Following this approach does not mean that the inquirer ignores the influence of social constructionism on the stories that we tell ourselves and others. As Chase (2005, p. 658) states:

> While acknowledging that biographical, social, cultural, and historical circumstances condition the stories that people tell about themselves, narrative psychologists look for evidence that the stories that people tell affect how they live their lives. They emphasise the

> 'formative effects of narratives' and propose that some stories cripple, and others enable, an efficacious sense of self in relation to life problems or traumas.

I was curious to know how my co-narrators saw themselves in relation to my sister with autism, and how they developed their sense of selves accordingly. The emphasis of this narrative approach was therefore on "*what* the story is about – its plot, characters and sometimes the structure or sequencing of its content," rather than *how* the stories were told (Chase, 2005, p. 658). On the whole then, I wanted to know how the co-storytellers perceived their realities and their meaning-making processes of their encounters with Leyna – what stories they told themselves about her presence in their lives. I delight myself in the following words of Eisner (1997, p. 264):

> Narrative, when well crafted, is a spur to imagination, and through our imaginative participation in the worlds that we create we have a platform for seeing what might be called our 'actual worlds' more clearly. Furthermore, when narrative is well crafted, empathic forms of understanding are advanced.

For me, then, to create a well crafted narrative research study, I had to familiarise myself with qualitative work, because the narrative paradigm falls under a qualitative research design. This will be briefly discussed in the next section.

A recapitulation of the research plan of inquiry

As discussed in Part 1, I decided on a qualitative plan of inquiry to inform my voyage of discovery. Qualitative research is used as an umbrella term for numerous approaches to research studies. According to Rogers (2003, p. 57), "[q]ualitative research is an iterative, exciting way to contribute to knowledge by telling a detailed, empirical, and theoretically interesting story about a particular project". As mentioned in the previous section, a narrative approach was selected to elicit these interesting, alternative stories. I selected a qualitative plan of inquiry, because it offered me the opportunity to select a way of working that fitted in with my interest and strengths, was congruent with what I wanted to study and developed my abilities as researcher (Eisner, 1997). This is exactly what I set out to achieve by choosing this research design. I used the following guidelines from Rogers (2003, p. 58) regarding good qualitative research before I started the planning:

- Good qualitative research is open to question and therefore transparent with regard to formulation of research questions, data collection, and analysis, revisions in process over time, and limitations of the research.

- [Qualitative research] … should be designed for particular contexts and provide enough detailed information to ground interpretations in a specific time and place.

- Qualitative research also highlights processes, for example, individual, social, developmental, and historic ways people construct meanings and act in the world – and therefore should clarify not only what happens in a particular time and place, but *how* it happens, and *how* meanings get created.

- [G]ood qualitative research commonly proposes multiple interpretations and raises new questions.

- Qualitative research addresses a theoretical puzzle through narrative data and methods of analysis – good qualitative research then goes on to elaborate on or challenge theory in a particular field across disciplines.

- Good qualitative research consciously grapples with the entwined (ethical) issues of power and responsibility in relationships with individuals or groups that are often more lasting and intimate than is commonly the case with quantitative research projects.

After I had orientated and familiarised myself with the qualitative ways of working and the characteristics that a narrative inquirer should strive towards, I could start with the first plan on the agenda – i.e. finding the co-storytellers for the study.

Recruiting the co-storytellers for the voyage

In Part 2 I discussed the issue of voice and how people with disabilities' voices are not represented in the literature because of impairments in communication. Jones (2007, p. 32) explains this in the following way:

> Narrative research requires the co-storyteller to have adequate communication skills in order to relay his or her story. However, many individuals with disabilities communicate in very unconventional ways, making traditional forms of narrative research inadequate for helping people with disabilities find their voice.

At the outset of this research voyage, I knew that it would be highly unlikely that my sister with autism would ever be able to communicate her feelings, needs and experiences with her own voice. However, I wanted to reveal something about her inspiration and contribution to my life story – to give her a voice, no matter how little, through the people who love her most. I decided to choose the people surrounded by her who could convey these stories in an honest, genuine manner.

The focus of the study was therefore on the narrative experiences of four people who had been directly involved in caring for Leyna over the years, as well as my own interwoven story. Furthermore, it emphasised sharing the true stories about the influence of her presence on our lives. The reason that I chose this small selection[7] was not to generalise my findings to a greater population, but rather because "[q]ualitative research questions tend to focus on process rather than variance, are specific with respect to place, and draw on a relatively small group that is not meant to serve as a sample of a larger population" (Rogers, 2003, p. 55). The purpose was to story these co-narrators' specific life stories, related to their specific contexts.

Firstly, I chose to be a storyteller by weaving my own story about my sister into this study. The reason for this was that I wanted to give her a voice because she cannot always make her own voice heard. I wanted all the voices of the people in Leyna's life to be heard and storied. I wanted to offer others the opportunity to see (dis)ability through an alternative lens.

The rest of the storytellers were chosen on the basis that they each had a significant relationship with Leyna. Let me rephrase: Each of them had been significantly influenced by her presence in their lives, and wanted to voice their experiences in order for others to understand more about people with autism. Therefore, this study

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[7] I replaced the word 'sampling' with 'selection', as "sampling carries the connotation that those chosen are a sample of a population, and the purpose of their selection is to enable findings to be applied to a population" (Polkinghorne, 2005, p. 139). The purpose of this voyage was not to generalise findings.

was based on a purposive selection, because this selection was "chosen on the basis of what the inquirer considers to be typical units" and "the strategy is to select units that are judged to be the most common in the population under investigation" (Bless & Higson-Smith, 2000, p. 92). These co-storytellers were chosen for a specific reason – i.e. they have specific life experiences regarding autism. They were not selected because "they fulfil the representative requirements of statistical inference, but because they can provide substantial contributions to filling out the structure and character of the experience under investigation" (Polkinghorne, 2005, p. 139). I therefore chose the people who are the closest to her and who know her the best – her father, mother and sister, as well as her teacher who had been involved with her for the past three years.

The family members and teacher were told that they had been selected as possible co-narrators in this study because they had been part of Leyna's life and could contribute to the alternative stories that exist when being in a relationship with a person with autism. They received a consent form in which the details of the study were explained to them. They received both the consent form and the guidelines to the questions (see Addendum C) in the initial meeting. There I explained the purpose and my curiosity regarding the study as well as all the practical arrangements. I gave them time to read through it and to think about any uncertainties or questions that they might have about the study. After this, I had a follow-up meeting with each of them to answer their questions and address their concerns, and if they gave their consent to be a co-storyteller we made arrangements for our first discussion.

If they then agreed to take part in this study, they would be asked to participate in discussions about Leyna's influence on their lives. There were at least two discussions of 30 to 60 minutes each with all of the co-storytellers. The time and location for the discussions were negotiated between the inquirer and the co-storyteller. The discussions focused mainly on stories about Leyna and what her presence has brought about in their lives. They were not forced to answer any questions and I assured them that they were entitled to withdraw from the study at any time. Their names were omitted for the purposes of confidentiality. The study was a completely collaborative approach, as they had the opportunity to be part of the whole research process – i.e. telling the stories, giving me advice on how to capture the essence of the stories, and

editing the stories with me after I had transcribed the interviews. This all took place in a particular setting.

The setting

It is important to keep in mind that "narrative inquirers treat narratives as socially situated interactive performances – as produced in this particular setting, for this particular audience, for these particular purposes" (Chase, 2005, p. 657). Therefore, the context in which the discussions took place was very specific. Mishler (1986, p. 82) also stresses the importance of considering the research setting, especially pertaining to the inquirer:

> The interviewer's presence and form of involvement – how he or she listens, attends, encourages, interrupts, digresses, initiates topics, and terminates responses – is integral to a respondent's account. It is in this specific sense that a 'story' is a joint production.

The inquirer's presence would, then, have an effect on the co-narrators as well, as they became aware that they had an involved audience for their story. This could lead "as a spur to more sustained reflection" (Murray, 2008, p. 119). The discussions were held at my home in order for them to take place in a comfortable, non-threatening, quiet environment. However, because of time constraints, I had to have one telephonic interview with Leyna's teacher. Although this was not ideal, she nevertheless shared some valuable stories.

The next section will explain how I gathered the stories.

Gathering the stories

As was mentioned earlier, in accord with the narrative approach, the interviews took place in the form of discussions. Therefore, the questions acted as a guideline for the "inquirer's listening" (Josselson & Lieblich, 2003, p. 267), and were not necessarily asked directly. However, I always kept the purpose of the study in mind while listening to the stories, because in the end I wanted to attend to my research curiosity. Furthermore, I did not only listen for these stories, but also encouraged the stories or experiences that I wanted to capture. In this approach I was motivated by Chase's (2005, p. 661) assertion: "When inquirers conceive of interviewees as narrators, they

not only attend to the stories that people *happen* to tell during interviews but also work at *inviting* stories."

I invited these stories by having discussions with the four people who had been touched by Leyna's presence in their lives. Narrative practices (such as respectful curiosity, the deconstruction of the problem, discovering unique outcomes and thickening the alternative story) were used to gather information that could potentially answer the research purpose. I had two individual discussions with Leyna's father, two discussions with our mother and sister together and one telephonic discussion with her teacher. Josselson and Lieblich (2003, p. 270) describe the narrative discussion in the following way:

> Narrative interviewing...requires that the interviewer keep her research aims and personal interests in mind, while leaving enough space for the conversation to develop into meaningful narrative. It has to 'procure' stories, namely concrete examples, episodes or memories from the teller's life.

Another important aspect that I had to keep in mind while having the discussions was that of power-sharing. In Part 1, I outlined the basic principles of post-structuralism in which narrative research is grounded. In structuralist times, there was a focus on the inquirer as the expert; who was seen as the one who had the power to 'unlock' the stories and assign meaning to the stories that others told him (Freedman & Combs, n.d.). This unequal division of power shifted with the post-structuralist movement where people were seen to be the experts on their own lives. This was relevant for my discussions with the co-storytellers:

> Opening up the research interview to extended narration by a research co-storyteller requires investigators to give up some control. Although we have particular experiential paths we want to cover, narrative interviewing means following co-storytellers down there trails. Genuine discoveries about a phenomenon can come from power sharing in interviews." (Riessman, 2004, p. 709)

I used power sharing throughout the process. The stories gathered during these discussions were recorded on a digital voice recorder and fully transcribed afterwards. To contribute to the principle of power-sharing and collaboration, the co-narrators were invited to read through the transcriptions afterwards and change, add or omit

something if they wished to do so. They were able to tell me if I interpreted what they said correctly and helped me with editing the correct meanings that they were trying to convey. For this to happen, I needed to have several discussions with each co-storyteller, depending on the themes that evolved throughout the interviewing process. For the purpose of this thesis a professional translator translated the transcriptions from Afrikaans to English and every attempt was made to stay as close to the original as possible. Atkinson and Silverman (1997, p. 305) point out that "[t]he open-ended interview offers the opportunity for an authentic gaze into the soul of another." My experience was also that it provided an important gaze into my own feelings and its effect on the research process.

As noted previously, I inserted a narrative account throughout the dissertation of my own experiences of having a sister with autism in addition to the discussions I had with the co-narrators. This was also part of gathering the stories. I followed the guidelines for the discussions myself for reflecting on my story of autism. I emphasised throughout this voyage that self-reflexivity is greatly important in a study of such a personal nature. Murray (2008, p. 115) emphasizes that reflexivity is part of the forming of identity:

> Narrative not only brings order and meaning to our everyday life but also, reflexively, provides structure to our very sense of selfhood. We tell stories about our lives to ourselves and to others. As such we create a narrative identity.

Keeping this in mind, I used the following guidelines from Etherington (2007, p. 614) about doing ethical research in reflexive relationships:

- To remain aware of the potential power imbalance between researcher and participants, especially where there are current or previous boundary issues created by dual relationships, and where there are issues of race, gender, age, etc.;

- To negotiate research decisions transparently with participants, and to balance our own needs with those of participants and agencies involved;

- To provide ongoing information as it becomes available, even when that requires the use of appropriate and judicious researcher self-disclosure;

- To include in our writing and representations information about research dilemmas that may occur, and the means by which they have been resolved.

In Part 5 I will share these personal reflections as I grappled with my identity as both inquirer and storyteller. I will also share the difficulties that I sometimes experienced in this dual role.

Such a personal study also brought forth the question of when the appropriate time was to stop the discussions. According to Josselson and Lieblich (2003, p. 267), it is a difficult task to know when to stop the discussions and to know when you have gathered enough information for the purpose of your study. They point out that the inquirer never reaches a saturation point in his or her work since "every person has a unique story and there is always something new to be learned. Rather, we stop interviewing when we 'feel' saturated …" I took their words into careful consideration, and gathered enough information to write up my story and address my research curiosity. After the discussions, I was amazed at the number of alternative stories that were told in the relatively short discussions that we had had. I then had to transcribe all of the stories and make meaning of them in some way in order to give a rich description of the alternative stories that I had gleaned through my relationship with Leyna.

Making meaning of the stories

The next pivotal part of planning the voyage was the way in which the stories were to be analysed, or, as I prefer to call it in narrative terms, the way in which meaning was to be made from the stories. Rogers (2003, p. 57) explains that in order to choose appropriate ways in which to create meaning from the told stories, "[s]tudents must grapple with an array of data analysis tools and select ways of working that do not obscure the richness and complexity of qualitative data". In narrative meaning making, it is important to remember that the purpose is to gather the focal narrative account (Murray, 2008). The inquirer wants to make meaning of the stories and use this evidence to retell the core description of the accounts given (Polkinghorne, 2005). In this case, I transcribed the stories obtained from the discussions through thematic analysis (thematic meaning making).

I divided this process of meaning making into two broad phases – i.e. firstly descriptive and then interpretive. Before each phase, I read through the transcriptions thoroughly to get the gist of the stories told. This allowed me to highlight the key themes in the text and helped me to identify narrative connections between the different accounts (Murray, 2008). I was guided by Riesmann's (2004, p. 706) observation that in this type of meaning making "[e]mphasis is on the content of a text, 'what' is said more than 'how' it is said, the 'told' rather than the 'telling'". In other words, I did not follow a discourse analysis to determine how my co-storytellers created meaning for their lives. Rather, I was more interested in the story itself than how they constructed the meaning of the story. This was the second phase of the meaning-making process – i.e. linking the narrative with the broader theoretical literature. This also meant that I had to keep the theoretical assumptions that guided the meaning-making process in mind, as well as being open for new emerging themes and ideas (Murray, 2008). Therefore, I agreed with Riesmann (2004, p. 706) that "[t]he thematic approach is useful for theorising across a number of cases – finding common thematic elements across research co-storytellers and the events they report". By following this approach I hoped to find themes that would bring me a step closer to answering my research curiosity.

As I said in Part 1, the purpose of the study was to story experiences specifically pertaining to autism, not to analyse *how* the stories were told (e.g. the language structures of the stories) being told. Because I was interested in the content of speech, I wanted to interpret what they had said by focusing on the meaning to be found in each story. I therefore regarded language as a resource, and not something that needed to be investigated (cf. Riessman, 2004, p. 706). Furthermore, since I saw this voyage as a collaborative one, I invited my co-storytellers to join in the meaning-making process. I wanted them to feel part of the storying process as much as possible. They were encouraged to check the transcripts and to comment on my interpretations, especially where I depicted the themes that I regarded as the most prevalent. In summary, I wish to point out what Chase (2005, p. 657) has to say: "As narrators, then, inquirers develop meaning out of, and some sense of order in, the material they studied; they develop their own voice(s) as they construct others' voices and realities ..." This adheres to the purpose of the research voyage again, namely giving voice to Leyna, a person with autism, by sharing our own voices of our experiences with her.

In the light of this viewpoint, Chase (2005, p. 664) has developed a typology of three voices that narrative inquirers can implement "as they wrestle with the question of how to use their voice(s) to interpret and represent the narrators' voice(s)". These voices are the authoritative voice, the supportive voice, and the interactive voice. I found this to be especially true for a collaborative relationship such as the one that I envisaged. I will briefly describe each of these voices.

The authoritative voice "connects and separates the inquirer's and narrator's voices in a particular way ... in the text they create, inquirers connect or intermingle their voices with narrators' voices" (Chase, 2005, p. 664). Within this typology, the inquirer's voice and/or interpretation becomes the predominant one, although still respecting the narrator's voice. The supportive voice, on the other hand, "pushes the narrator's voice into the limelight" (Chase, 2005, p. 665). Here only the interpretation and storying of the narrator becomes relevant and the inquirer steps aside to allow the narrator to be the main voice in the story: "This narrative strategy aims ... for creating a self-reflective and respectful distance between inquirers' and narrators' voices" (Chase, 2005, p. 665). It was inevitable that both of these voices of interpretation were used interchangeably throughout the storying process. However, within the collaborative approach that I strived towards, I tried to focus on the interactive interpreting voice.

The interactive voice, then, "displays the complex interaction – the inter-subjectivity – between inquirers' and narrators' voices. These inquirers examine *their* voices – their subject position, social locations, interpretations, and personal experiences – through the refracted medium of narrators' voices" (Chase, 2005, p. 666). This again connects to the idea of self-reflexivity, and how important it was for me as the inquirer to be aware of my own feelings and biases when interpreting others' voices. Chase (2005, p. 666) furthermore emphasizes the following notion within the interactive typology:

> [I]nquirers make themselves vulnerable in the text. They include extensive discussions of their emotions, thoughts, research relationships, and their unstable interpretive decisions ... they ground these practices in the idea that inquirers need to understand themselves if they are to understand how they interpret narrators' stories *and* that readers need to understand *inquirers'* stories ... if readers are to understand narrators' stories.

In the light of the personal, emotional accounts that were recorded, I could not help but wonder about the notion of truth and subjectivity. What was the 'truth' in the stories that were being told? Who said it was the truth? Who determined this? In the next section I attempt to answer these pivotal questions about validity in narrative research.

Validity

The importance of the validity of information gathered is not a new concept to the field of research. In traditional, positivistic research, it has been present for many years, and pertains to the believability of a knowledge claim (Polkinghorne, 2007). There is, however, quite a difference when speaking about validity within the traditional social science community, and the post-structuralist community. Polkinghorne (2007, p. 472) explains the latter:

> The theme of the reform movement is that there are important aspects of the personal and social realms that cannot be investigated within the limitations of what has been conventionally accepted as evidence and arguments used to justify or validate knowledge claims. The reformists, who include narrative inquirers, posit that evidence, such as personal descriptions of life experiences, can serve to issue knowledge about neglected, but significant areas, of the human realm.

In other words, within narrative research, the argument is that one cannot break evidence into structures that can be explained and 'measured' by science alone. They argue that there is a great gap that only life experiences and stories of these experiences can fulfil. However, evidence is still needed in order to support the knowledge claims that are made to give them some sense of credibility. Polkinghorne (2007) argues that validity is not a definitional concept, but rather a 'prototype' concept. He suggests that there are degrees of validity, rather than the restricted 'either … or' dualism of the term. He furthermore allocates the threats on validity in narrative research to two areas, namely "the differences in people's experienced meaning and the stories they tell about this meaning, and the connections between storied texts and the interpretations of text" (Polkinghorne, 2007, p. 471). It was on the validity within these two areas that I focused, as it was specific to the research voyage that I envisaged.

Cho and Trent (2006) name two methods of promoting validity within qualitative research, namely member checking and triangulation. In addition, a theoretical or availability selection was used to further promote validity. These are three methods that I incorporated within my study in order to raise its degree of validity. *Member checking* again emphasised the collaborative relationship between me and my co-narrators: "Member checking occurs throughout the inquiry, and is a process in which collected data is 'played back' to the informant to check for perceived accuracy and reactions" (Cho & Trent, 2006, p. 322). This gave my co-storytellers the opportunity to change what they had said, explain it in more detail, or elaborate on some of the details about which I needed more clarity.

The second method of contributing to validity in my study was that of *triangulation*. Denzin (1989, p. 236) defines it as "the use of multiple methods ... [to] partially overcome the deficiencies that flow from one investigation or one method". I used discussions, observing within the discussions, as well as cross-checking information from different discussions held at different times as methods to see whether these aspects showed a relationship with each other. Henning, Van Rensburg and Smit's (2004, p. 103) noteworthy statement emphasises that "it is not only in the use of a variety of data collection methods and sources (triangulation) ... but also in the use of different approaches to 'working the data' or building the interpretive text, that the strength of an inquiry (validation) is built". Polkinghorne (2007, p. 475) adds to this when he says that "[v]alidation of claims about understandings of human experience requires evidence in the form of personally reflective descriptions in ordinary language and analyses using inductive processes that capture commonalities across individual experiences". In other words, I needed to find a golden thread through all of the stories told (including my own), to ensure that my study would have a degree of validity. This asked for sound ethical principles before I started the voyage.

Ethical considerations

I was well aware that there were several ethical issues that needed to be considered when starting this research voyage. The main ethical consideration for me was the protection of my sister's well-being and needs.

I will give a short description of my sister, Leyna, in order for others to gain a better understanding of her as a being. She is an 18-year-old adult currently living with my mother. She finished school last year. She was diagnosed with a Pervasive Developmental disorder when she was three years old. She was also diagnosed as severely mentally handicapped as a co-morbid disability. She has very little speech and communicating with her is a challenge. Despite all of this, she does understand what is going on around her and she knows when others are talking about her. There is thus nothing wrong with her receptive language and language-processing abilities. Understandably, this made her vulnerable when doing a study of such a personal nature.

As said earlier, ethical clearance had to be obtained in order for this study to proceed. To comply with their specifications, an external monitor was appointed to ensure that Leyna's best interests were always taken into account. The monitor who was selected was briefed about the purpose of the study and all the ethical considerations that needed to be taken into account. Her role was to read through the transcriptions of all the audio recordings of the discussions with the other co-narrators, with Leyna's well-being constantly in mind. Afterwards, using her professional experience, she gave me feedback on the discussions that would protect Leyna. This was done in order to provide a piece of work that was empowering to all of us, including my sister. Her feedback, which included ideas and questions for further discussions with the co-storytellers, helped me elicit more stories in order to thicken the alternative stories about having her in our lives. Her role was further to read the parts in my thesis on the findings, recommendations and conclusions of the study, to make sure that Leyna's integrity and interests were always being put first. She wrote a short report in which she gave feedback on this aspect (see Addendum B), and I made the necessary adaptations in order to protect my sister. The monitor was paid an hourly rate for her services, with the funding from the NRF bursary. The payment details were discussed with her and a contract was signed in which she agreed to participate in this study. In the contract she gave her consent to protect my sister at all times, to safeguard any information that would be obtained during the study and to protect the confidentiality of all the co-storytellers.

My sister was also asked to give her verbal consent (on her level of functioning). This meant that I asked her if I could write a story about how much she means to us as a family, and how she has changed us all for the better. I informed her of this and in her own good-natured way she indicated that she understood. I obtained written consent from both my parents (as her legal guardians) to give permission on her behalf for this study to proceed. Both of them were of the opinion that this study would not harm her, but rather make us as a family more aware of the positive impact she has had on our lives. They also felt that this was an ideal opportunity to tell others who are in similar situations that not everything is a struggle and that one does not need to live by a negative (struggle) discourse.

It was decided that Leyna would be identified in the study as my sister. However, her name was changed to maintain a certain level of confidentiality. The reason for this was that I wanted this study to be real and tell all the details. If I said that she was a 'family member', the meaning that the co-narrators and I created together could have become so vast that it would lose its credibility. I therefore wanted to provide the true context in which our family's meaning was created. It was also decided that it would be in my sister's best interest not to be present in the interviews. This was firstly because it would not always be geographically possible to have her there, as she was on the waiting list for a few homes that supports adults with autism, and she might have been accepted there at any time. Furthermore, because she cannot sit still for very long, it would possibly be inconvenient for her to sit still and listen to what was being discussed.

Most importantly, it is found that within a narrative approach, people sometimes still live their lives according to problem-saturated stories (as discussed in Part 1). This means that there was the risk in this study that co-narrators could share the difficulties that they experienced while living with or knowing Leyna. If she had to hear these stories, it could hurt her feelings and have an impact on her well-being. It was the aim of the narrative inquirer, however, to listen for the alternative stories and elicit conversations about these stories to create new meaning for the problem stories. Although the intended outcome of the discussions was to story alternative experiences about her, it could have harmed her if she had to be present in the interviews. It was therefore for her own protection not to be part of the discussions, but rather to hear the

final, alternative story about her impact on our lives. I personally shared the findings (‘alternative stories’) with her when the research process was completed. She therefore had access to the final results of the study.

Informed consent was obtained from the co-storytellers before having the discussions. The purpose of the study was thoroughly discussed and explained beforehand. I also discussed the confidentiality involved and the limits of confidentiality, especially regarding the dissemination of the results. The limit to confidentiality of this study was that the co-storytellers could possibly be identified because of their relationship with me, as my identity is revealed as well as my sister’s. They were also asked to provide informed consent for the external monitor to listen to the recordings. I explained the external monitor’s exact role, the reason why we needed her involvement in the study and her responsibility to safeguard the information obtained and to keep all data confidential.

The guidelines for the discussions were sent to them with the consent form beforehand, so that they could have a thorough understanding of what the expectations were. This gave them an opportunity to decide whether or not they would be comfortable with participating. During the discussion, the co-narrators were free to share only the information that they wanted to. Furthermore, I obtained permission to record them on the digital voice recorder. The names of all the co-narrators were omitted so that they would remain anonymous. However, their relationship to Leyna was revealed – i.e. whether it was her mother, father, sister or teacher. I told them that the purpose of storying these discussions was not to cause any harm to Leyna or the co-storytellers, and that great care would be taken to prevent this from happening. As stated previously, this would be the narrating of alternative stories which would be empowering and enlightening for us as a family, the co-storytellers and especially for my sister.

Reflection on the modes of inquiry

I started out this part by highlighting the main considerations when planning a research voyage while working in a qualitative, narrative approach to a study. I explained the procedures that I used in finding the co-narrators, choosing the research setting, gathering the stories, and writing up the stories. These raised some more

important issues that needed exploring, such as the validity of the information gathered and also the ethical considerations that needed to be taken into account. The next section will explore the findings and tell the stories as they emerged after all the above-mentioned measures had been implemented.

Part 4

What the stories reveal

The Joy of autism
because finding joy doesn't come without struggle;
because the point is to find it;
because if an autistic person calls autism their way of being, not an illness, then it is;
because every human has value and is a joy;
because despite inhumane acts, I believe in humanity;
but most of all, because of my son Adam.

Klar (2005)

I have to agree with Estée Klar (a mother of a son with autism) – the stories that were told during this voyage depicted narratives of great challenges and difficulties, but, more importantly, they were alternative accounts enriched with immense joy and personal growth. This part of the voyage will portray these tales according to themes that were found after the analysis of data – or rather how meaning was made through telling stories – as was discussed in the previous section.

The road towards acceptance

> *"… I once again asked, 'Why me God?' With my fists clenched – my mind in victim mode – tears wet my pillow. How could this happen to me? And then, I heard a big, yet little, voice saying to me, 'Why not you, Keri? Why not?' At first I was startled; then a knowing came over me. My time to learn acceptance had come." (Keri Bowers, quoted in Stillman, 2008, p.16)*

As I sat with my father in our first discussion, it was for the first time that I really saw the experience of caring for someone with autism through a parent's eyes. I realised that this voyage of raising Leyna has been an incredible hard one to endure, and I have to give credit to that. I am not going to tell you in this study that knowing a person with autism is easy. It has been a very hard road to travel, and in all the conversations that we have had, there have been tales of immense hardship and sacrifice. And these difficult times will continue to face us in the future. However, have I called this sub-section, which is concerned with hardship, "The road towards

acceptance," because, as this voyage continues, you will come to see that despite all of these hardships, alternative stories do exist – and it is these stories that ultimately make us stronger. Nevertheless, one cannot ignore or omit the more difficult stories, as all experiences contribute towards the way in which we create meaning for ourselves and see our realities.

If one looks at the bio-ecological paradigm, it is interesting to realize how these stories of hardship are imbedded in the context, and how the different levels of systems have played a role in these stories about Leyna. This links with Burr's theory of social constructionism, as discussed in Part 1. Our world and the ways in which we attach meaning to things are not constructed in a vacuum. Rather, our worlds are constantly being reconstructed by society and the influences around us through language and cultural power. It will be useful, then, to mention the main barriers of hardship and deconstruct them within the bio-ecological paradigm.

The quotes presented in this part have been translated from Afrikaans. Every attempt has been made to stay as close to the original as possible.

The first barrier that came out of the discussions was the inability of professionals to make a definite diagnosis. When Leyna was a young girl, information about autism was scarce. It was a rare condition. My parents went from professional to professional, but nobody could give a definite diagnosis. This contributed to the parents' struggle to accept it and move on, because nobody could tell them what her condition was.

Father*:* *And there was not really a diagnosis, which made it very frustrating, because they did not know what was wrong. However, at a certain stage we realised that something was wrong – she was not going to develop normally …*

It is clear that a huge barrier existed on a macrosystems level (See Figure 2.1), as limited information and expertise on autism was available. Everybody was in the dark about this matter. However, this has since started to shift as autism becomes more and more prevalent.

Another barrier, which especially affected the other microsystems immensely, was Leyna's difficult behavioural patterns. This could be described as an internal barrier,

as it has to do with the person with autism's complicated neurology and impairment in communicating their needs. Experts sometimes explain difficult behaviour as problems with sensory integration. When Leyna becomes frustrated and cannot tell one what is bothering her, it is almost as if she exhibits difficult behaviour as a cry for help and attention. Of course, this is only my point of view and how I make meaning of it for myself. Her teacher also reframed difficult behaviour as it pertains to her, by stating the following:

Teacher: *Do you know what we can also sometimes pick up … that they have feelings and that they are trying to get closer to you when they have these tantrums. This also tells you that they are also seeking attention; they have need of love, even if they don't always want you to touch them.*

The teacher firstly acknowledges that people with autism also have feelings and they do seek affection. She sees difficult behaviour as a way in which people with autism seek attention and love, which are not necessarily the same as our (neuro-typical) conventional ways of eliciting and showing physical affection.

Another barrier that was mentioned (with quite a lot of emotion), which contributes to the hardships on a daily basis, is society's lack of understanding of and ignorance about autism. Although a lot of information has been shared in the media recently and celebrities with such children, (e.g. Ernie Els, Chris Vorster, Sylvester Stallone and Jim Carrey have come forward to speak out for the autistic community (Tancred, 2009, pp. 9, 15), it seems that people still stare and make rude comments when a child is 'different'. During the discussions, this brought many emotional responses such as anger and sadness to the fore.

Another barrier relating to the difficult times is the lack of support from friends and family that all of us experienced. This again relates to the macrosystem as described above, where there is a global lack of knowledge (and often insight) about autism. My father agreed that it was difficult for him to share his difficulties and feelings about her with others, as he felt that others would think that he is seeking sympathy. My mother also acknowledged that she might have assumed that her friends knew more about autism than what they actually did. Therefore, a barrier in the mesosystem existed – a communication blockage between the different microsystems. Personally,

I was often angry because people did not understand. As a typical teenager I struggled to invite friends over because I was afraid of what they might think or say. I rather mumbled something quickly to new visitors like, “She’s handicapped” and then ignored her the rest of the time. As I think back, I realise that they must have wondered about her quirky behaviour. I wish I could go back in time, knowing what I know now, and explain her ‘condition’ to them – tell them why she does certain things and acts strangely sometimes. However, I did not understand (I still do not most of the time), and acceptance is a voyage – it takes a few mistakes to realise that what she has is not a condition, but a gift.

A further barrier on a macro-level is the limited resources available for people with mental disabilities, as opposed to those with physical disabilities. Unfortunately, it is a reality that a person with a severe cognitive handicap cannot contribute in a workplace as much as a person who is, for instance, in a wheelchair or who is blind. I do not think there is an answer to this dilemma; it is just simply a difficult barrier to cross. Maybe, in time, there will be an answer, or society will become more accommodating for this special group of people. In the meantime, we can just accept them for who they are. As my father said in the interview:

Father: *... uhm ...* accept *it and … do the best you can with her … limitations …*

My father’s positive attitude of acceptance became clear after he said that one should just accept that she is not normal, and that one should do the best one can with her limitations. This is exactly what we, as her family, did.

As noted in Part 2, the bio-ecological paradigm still breaks experiences into structures. Therefore, I used the above breakdown as a means of explaining the dynamics between different people and systems to the reader. It is important to keep in mind though that the post-structuralist paradigm takes into account all the complexities in life created from experiences.

In conclusion, I wish to say that we, Leyna’s family, have made many sacrifices for her throughout the years. It has been painful, and it still is some days. However, we do not choose to live our lives according to a problem-saturated discourse. Once again, I have to agree with Klar (2005) when she says that finding joy does not come without

struggle. We know that. We have been there. We still are. Nevertheless, we have found joy, and it is these stories of joy that I would like to share with you now all the way through to the end of this part of the research voyage.

Our understanding of autism

It was important to me to inquire about the context or the lens through which the co-narrators view autism – what it means for them and how *they* understand it. I explained my stance toward autism in Part 2, when I concluded that autism comes with its own challenges and strengths, and that one should not call it a disorder just because it is different from what we know. However, this does not mean that my co-storytellers see it in the same way. As was discussed in Part 1, I tried to invite stories from the co-storytellers over and above just listening to stories begin told, because I know the importance of power sharing when working within a narrative paradigm.

From the discussions, my co-narrators gave quite a few examples of the things that they believed contributed to Leyna's autism. They also spoke of their own confusion and struggle to understand her. Her teacher described her as an autistic, non-verbal learner (although she has some single words),while my father mentioned that she does not fit in with his understanding of what classic autism is – i.e. somebody who is in their own little world, rocking himself or herself in the corner. My mother shared her confusion about Leyna's mental age and her understanding of others. There are, for instance, things that Leyna really struggle with, like language and basic activities. However, some days she will completely surprise you by commenting on things that you thought she would never understand. From my own perspective, I am also confused as to how much she understands. Sometimes I think that she will not notice that I am gone, but then she knows all of our names and even calls out our nicknames when we are not there. Another thing that both my parents mentioned was her sensory sensitivity to loud noises.

Father: *Uhm, I told them about the lawn mowers. I don't think I have referred to this before, but she has an absolute fear of and a … and a … fascination with a lawnmower … and noise. (Laughs.) ... How it influences her if I have to work with a drill and such things. Those kinds of things – to such an extent that I have swopped my petrol lawnmower for an electric one because it's less noisy!*

Inquirer: *(Laughs* – remembers *this.)*

Father: *(Smiles.) We even had to take turns in taking Leyna to the shops while I quickly mowed the lawn – that kind of thing to get past these kinds of problems.*

In the excerpt above, my father highlights her sensitivity to drills and lawnmowers and the noise they make. In addition, my mother explained that she gets very difficult in a big shopping centre because of the loud noises and the echoes of the sounds.

Mother: *And in a shopping centre I always tell them that they (people with autism) hear much better, I explain to the people ... uhm, they can hear things that our ears shut out, and then that makes her feel anxious …*

Inquirer: *(Interrupts.) Yes, a sensory overload! It is as if they can't distinguish between what is near and what is far – they just hear the whole echo of the whole mall, and it's just an overload – literally.*

My mother would then just explain to the people around her that Leyna can hear much better than they do, and that it makes her very anxious. I agreed with her and explained the sensory overload that people with autism experience.

Another thing that I enquired about was the (mis)conception that people with autism do not form bonds or relationships with others. All my co-narrators confirmed my view. Although the bond is not necessarily formed in the conventional way, it does exist, and it is strong. As her teacher said – deep down they all do have feelings.

Teacher: *It is said that they do not necessarily form a bond, but deep inside they do have feelings, even though they do not show it with hugs and kisses …*

Something else that my family could not understand was, for instance, her insistence to use the same things. She would only drink from the same cup and eat from the same plate, using the same cutlery. My parents even had to glue her plastic Mickey Mouse plate together when it broke, because she refused to eat from anything else. She showed the same behaviour when the seasons were changing, and she refused to wear her winter clothes. The transition seemed too much for her, so my mother had to start putting out her clothes on her table for the next season, just so she could get used to them.

From the information and discussions gained in this section, it became clear that autism is very difficult to define and understand – even for the people who live closest to people with autism. People with autism are unique. I do not know whether we neuro-typical people will ever come to a full understanding.

A special relationship

There are so many stories that I can share in this particular section, about the special bonding relationship that Leyna has with each one of us. I am only going to share a few of them, and then just briefly summarise the gist of what was said concerning this theme.

All the stories that were told bear witness to the meaningful relationship that Leyna has with all the people that are close to her – to those who really know her. It seems that she has even left a lasting trail behind in her school.

Teacher: *Her presence caused her class mates to miss her when she wasn't there … if she happened to be absent, her classmates could in fact … they did indeed miss her… one specific boy would say, "Leyna is on holiday, Leyna is on holiday."*

Above, her teacher explains the reaction of her classmates on days when she was absent. Her classmates did in fact realise when she was not there, and they all missed her. I also enquired about Leyna's special relationship with the class assistant. I know that Leyna had a very close bond with her, because she would sometimes say her name after school with a smile, and the assistant always gave her presents and cards. I heard from my mother that the school staff nicknamed Leyna "The Bride," because she was always holding onto the assistant's arm. I asked her teacher about this, because I knew there would be a good story to tell.

Inquirer: *Yes, because I know Leyna and the assistant were so … my mother told me that they … if Leyna and the assistant came along they always called her 'The Bride" or something like that, because they always walked arm in arm.*

Teacher: *Yes, oh yes, she was … er … the assistant's shadow. Wherever the assistant went, there you would also find Leyna; wherever the assistant was, Leyna would also be right there, yes.*

Her teacher smilingly said that Leyna was like the assistant's shadow. She explained that the assistant had a soft spot for girls (there are far fewer females who are diagnosed with autism than males), and especially for Leyna.

I also know that my mother and Leyna have a special bond. I rarely see the one without the other. This was my mother's story when asked about this.

Mother: *Yes, for example, if there is a domestic worker who is doing the housework and I am at work or whatever, then she'll sit on that couch the whole day and not worry them at all, they can just go ahead with their housework … But when I clean the house she's everywhere … every step I take I am just about in* ***her*** *way! (Smiles.)*

Inquirer: *Yes, because the way I see it you and Leyna are very … yes, joined at the hip. (Laughs.)*

In this instance, my mother used the example of when she is doing chores at the house. When the domestic worker is doing her work, Leyna will just sit quietly on her couch. However, when my mother does her chores, she will follow her from room to room and make her feel that *she* is in the way! This reminded me of how Leyna will follow us from room to room when everybody is at home. She has such a curious nature, and it seems that she does not want to miss out on anything. She will start at my room, check what I am doing, and then leave. The she will do the same with my sister and my parents. It is a distinct little route that she follows, and she will do this continually, until all of us sit together again. To me, this is evidence that she does care for us and that she treasures the relationship we have with her.

On a lighter note, our middle sister explained her relationship with Leyna as beneficial, because she is a good accomplice when it comes to getting things from our parents! She has them wrapped around her little finger. For instance, when we want take-aways, we know that if we sing a take-away song, she will go and tell our parents, and then our parents will think she is so cute and will not be able to say no to her. We even taught her the words of the song, as she is very fond of music and learns songs easily. She is also very fond of food!

Sister: *That McDonald's, McDonald's, Kentucky Fried Chicken and a Pizza Hut ... you always just sing that song and then she finds them and sings it to them [parents]. Because she's always very keen to convey it to them …*

Other stories that were told around the theme of our special relationship with Leyna were related to our protective nature over her, our deep love for her, and our enjoyment of her unique, quirky personality. There were so many stories told about her unique personality that it will be discussed next as a separate theme.

Leyna's unique personality

I find that the most striking aspect of Leyna's personality is her genuine nature – her unconditional love and complete acceptance of a person. She has this innocence about her, almost childlike, that is completely pure. I think that is one of the privileges of knowing a person with autism – there are no pretences, one can just be oneself. She is also an exceptionally sensitive being; actually very finely attuned to others' emotions. Moreover, she was described as being both loving and lovable. She does not become attached to just anybody, and the bonds that she forms with others are truly special and genuine. My mother mentioned that she does not ask for much but a little love and attention.

My co-narrators described Leyna as a friendly girl who is excited about things and has the capacity to enjoy herself. Her sense of humour and 'fun' personality was mentioned as well. We have a saying in our home that with her around, there is never a dull moment. My sister mentioned her smile – something that all of us hold very dear to our hearts. That smile of hers can melt anyone's heart. An overall theme that came out was how cute and delightful all of us find her. No matter how angry you get at her, she will always do something sweet straight after, that will just melt your heart – be it a song that she sings, her laugh or just her mimicking your angry tone of voice.

Furthermore, her way of communicating with us is worth mentioning. She uses her own vocabulary of single words or two-part sentences to tell us what she wants. The funny thing about this though, is that she has learnt that we think she is adorable when she uses diminutives ('baby words') when she asks for things. In Afrikaans, diminutives are often formed by the prefix *-tjie*. She will for instance say "*Mamma-*

tjies" for Mommy, "*Honger-tjies*" for hungry, or "*Val-tjies*" when someone has fallen down. This makes her irresistible and she knows it.

Earlier on, I described her personality as being quirky. One of the quirky things that she does is to store her most precious belongings in the fridge. We refer to it as her treasure chest. When my sister mentioned this during the discussion, we could not stop laughing.

Sister: *No, best of all is the way she stores all her precious belongings in the fridge … (Laughs.)*

Inquirer: *Yes, it's her treasure chest! Like half-eaten food …*

Sister: *And stuff that she made at school, like that plastic bottle with the flowers in it, her toothbrush, her favourite dolls … Then she'll put them in the fridge for the night, and she'll say "Night-night" and kiss them!*

(Everybody laughs again.)

Inquirer: *Or worst of all … she breaks all Mommy's cups, and then she'll keep one cup just for herself and put it in the fridge!*

When she was small, another peculiar thing that we could never understand was her intense fear of cows. She could not stand any pictures, songs, dolls, pyjamas, or anything depicting cows. She would say, *"Bang vir koeie, bang vir koeie!"* which means "Scared of cows, scared of cows!" even sometimes when there were no cows in sight. We had to sympathise with her for endless hours and tell her not to be afraid, that the cows cannot harm her, that they are sleeping, and so forth.

My family portrayed her as being quite a fashion-conscious 'lady' who enjoys being pampered and wearing nice clothing. She is always first in line when my mother paints her toenails, and she loves putting on others' cream and perfume. She also has a great love of food – especially healthy things like a home-cooked meal, fruit, and vegetables. My father told a story of her curious nature, especially when he brings shopping bags home from the grocery store. She will immediately hear the sound of the packets and come closer to investigate what nice snacks there are for her.

The last thing that was mentioned by all of the storytellers was Leyna's love of music. The number of songs that we have made up for her is endless: songs about drying her hair, songs about eating food, and songs about cows – that she should not be afraid of them. The list goes on. She enjoys music immensely, and has a few favourite songs that she will listen to over and over again. Our knowledge of children's DVDs is excellent, and we know the words of the songs off by heart.

I hope that after this section you now have a better understanding of who Leyna is. As you have probably noticed, we all enjoy her company greatly and this was a wonderful opportunity to celebrate the unique person that she is. In the next section, I will tell the stories of people who have given her support and acceptance.

Other people's contributions

Although it was mentioned in **The road to acceptance** that there was little support from friends and family, it became apparent during the discussions that there were also people who made significant contributions to the family's lives. I therefore thought this a good opportunity to reframe the alternative stories to the previous ones told, and document them to add to the purpose of this study.

My middle sister and I both have a best friend who always came to visit us – no matter how difficult Leyna's behaviour was on a particular day. Both of them accepted Leyna for who she was, and what was striking is that my sister said that her friend treated Leyna as if she was not autistic, but just as if she were any other human being. In this instance, the interactions between the different microsystems had a more constructive and encouraging influence on the other systems, as opposed to what was mentioned earlier in Part 4.

It does seem that people are more informed now than they were 20 years ago. My mother mentioned that it is far easier to go to a public place with her – when she explains Leyna's autism to them they immediately know what she is talking about and are generally more accepting of her behaviour.

Then, a story that is dear to my heart is about something that happened quite a few years ago. As a family, we were on our way for a holiday in the Kruger National Park. My parents needed to buy groceries for us, and my sister and I stayed in the car with

Leyna. However, after a while, she needed to go to the bathroom, and we had to take her into the very busy mall. She was very anxious and vocal, and we made quite an entrance (as usual). Most of the people stared at us, but there was one woman who came to my sister and me and said the most beautiful words to us. She said Leyna is a blessing in our lives, and that we would one day see the purpose of why she was present in our lives. And she was right – I do see the purpose now, which I will share with you later.

Message to the community

One of the themes around which the stories were told, was that we, the storytellers, wanted to give a message to the wider community. I now realise that this is in part why I decided to do this study: I wanted to share with the wider community the blessings that we have received, and tell about Leyna's unconditional love for the people around her. This is something that I would really like others to know. Clearly, a great part of the message was for the community or the general public, to make them aware that they should be more open to people with autism and their families.

Father: *... she's just special because she can't … can't help being what she is. Uhm, it isn't her fault … people must just [try to] understand more …*

People should try not to judge and rather show compassion and understanding. Leyna cannot help who she is and she cannot help when she experiences difficulties – especially when she becomes anxious in public. It is not her fault. And we want others to realise this.

Even more important than all the stories that have been told so far, are the stories of personal growth and change in the lives of all who have been touched by Leyna. This will be elaborated on in the following section.

Stories of personal change and growth

Personal change and growth was by far the greatest theme that came out – the alternative stories that I was searching for as I began my voyage of research. This was quite difficult for me to analyse, and I found myself at crossroads: Would I once again group the stories into themes as was done thus far, or would I portray each one's

individual voyage of growth? Then I decided: No – this is about everyone's individual tales that form part of the collective alternative story. I wanted you, the reader, to hear every person's story, because this is what makes it rich and that is how that specific person assigned meaning and purpose to knowing Leyna.

Our father's story

When I asked my father to tell me his story about how Leyna has changed his life, the first thing he said was that she had enriched his life in her own way, and that he cannot imagine life without her. He spoke about how difficult it was for him to live in Johannesburg, and how he missed her during the week; how he could not wait until the next time he saw her, which was about every third weekend.

Father: *Uhm what I miss about her is her ... uh … she brings me joy, she ... uhm ... I enjoy her ... in her own way she can make jokes and … that kind of thing. (Laughs.)*

When asked what exactly it was that he missed about her, he smiled and said that she brought him joy with her way of being – always joking in her own little way.

Another strong theme that emerged in his story was his strong feelings of protectiveness over her, as she cannot always look out for her own safety and well-being. When I asked him what lay behind his feeling of protection, he said it was his natural parental reaction and fatherly love for her.

Father: *Uhm, yes … I don't know … I don't know if the protection … I am tremendously protective of her … even now … since she has been with us, if we go somewhere together, then I am extremely protective. I am always aware of where she is … if she is out of sight for a moment then a minute later I'll begin looking for her and asking 'Where is she? What is she doing?' and that kind of thing.*

Inquirer: *I just wanted to ask you, Dad, what is the feeling behind that protection – that you want to protect her from the world?*

Father: *Well, I think it's a natural, parental reaction … love! I mean, in a normal family where there is love and so on, when you love your children … that feeling …*

While speaking to my father I realised that there had been another positive development. I became aware that he speaks more openly about her now. Where he felt as if he was seeking sympathy earlier in her life, he now talks about her freely and proudly to his friends and informs them about autism. His story of initial anger about other people's lack of consideration and sympathy also changed throughout the discussion to that of understanding and non-judgement. His reason for this was that he also had not known anything about autism before Leyna became part of his life.

Leyna's presence in his life made him much more aware of other people with disabilities. It made his feelings towards the disabled shift from sympathy to empathy, because he now knows what others are going through from first-hand experience. Leyna enriched his life by making him more vocal about autism and made him realise that everyone can make a difference in his or her own little way.

Father: *... so in that sense she has enriched my life, because you can, you can go and make a difference by [reaching out] to a lot of other people who may be in the same position … even if it isn't by giving money or anything like that, but just by being vocal about it … and by informing your minister or your member of parliament or something to that effect …*

Our mother's story

The first thing that my mother commented on was that there was *never* a dull moment with Leyna in our lives, and that our lives were everything but boring. There was always a crisis, or something to laugh about, something to clean up, or something to explain. Resting was a relative term in our household.

On a more serious note, my mother's story was one about patience and strength, and how her relationship with Leyna had made it possible for her to take on many challenges and show endurance until the end.

Mother: *Yes, indeed, I have gained more patience … I am able to [stand] more … I have probably become a much stronger person … I can endure far more …*

Inquirer: *Wow, I haven't thought about this. You learn to stand a lot [in life].*

Knowing Leyna also made her more appreciative of and thankful for the small things in life – things that others might otherwise have taken for granted. When she mentioned this, we all jokingly started to name the things that we do appreciate more. They included: to sit and drink a cup of tea in peace, to sit in a restaurant without people staring, to be in a shop that has changing rooms with doors that make it impossible for her to run into other people's cubicles! By this stage, we all burst out laughing. We experienced a kind of peace that made us realise that we are all in this together. And this made our voyage so much easier.

Our sister's story

My middle sister told me that because of Leyna's presence in her life, she became more attuned to other people's feelings, because she now knows what it feels like to be judged by others. I think she has had the most difficult time of us all, because Leyna demanded so much attention from our parents when she was younger. This information that she gave me was very precious and I will hold it dear to my heart – that despite everything, her story was still enriched with love for Leyna and for the people closest to her.

Sister: *I think … I am more considerate of others because of her. I am very closely attuned to the needs of others, and so on … I know what it feels like if people stare at you, and yes, … and then I feel no one can help doing it … if I … it's just that whole thing of 'I understand better' – I know what it feels like.*

This dear sister of mine is a very caring person with a very soft, sensitive nature and a compassion for others. In our discussion, we concluded that out of our caring for Leyna, a caring for others developed, which inspired us to choose careers where one puts others' needs before one's own. She is studying medicine and I am studying psychology. Furthermore, the two of us share a very deep and special relationship – maybe a sort of camaraderie that developed over the years. We are closer than most other siblings we know, and friends always comment about this.

Her teacher's story

When I asked Leyna's teacher how she became involved with autism, I was amazed at the wonderful story that she told me. She started out by working for different high

schools and primary schools, but never really settled at one particular school. Later she got a post as a teacher at a special needs school, and this is where she encountered autism for the first time, as two of her learners were diagnosed with the condition. After that, she applied for a job at an autism-specific school, and never left the field of autism. She has been working with learners with autism for 11 years now, and is still going strong. I knew there had to be an inspirational story here, so I asked her what difference autism had brought about in her life.

Teacher: *It isn't easy; many families break up, and they can't thrive socially. But I can also say that you have to keep your spirits up; you have to keep going … and every day you learn something new from that person. You come in every day and you learn something new!*

Although she acknowledged that it was a difficult reality, she spoke words of encouragement – that one should just endure and keep on going, because every day one learns something new.

Teacher: *Oh, they have just crept deep into my heart. They have made me appreciate life more; they have made me appreciate my child more; they make me appreciate my family more, because, yes, it is so difficult … and … I appreciate the time I have to myself; I appreciate the time I have at school; I appreciate the time I have at home.*

She obviously cared deeply for these children who had made her appreciate things more – her relationship with her own child, her family, her time for herself, time at school and time at home. The message that she left me with, was very empowering, and I would like to share it with others as well.

Teacher: *… but all parents and carers of people with autism, you are special people, and I just want to tell them they must persevere and keep up their courage, and everyone who works with an autistic person is a special person*

She gave a message of hope and of compassion to parents and carers of people with autism, because they are special people.

My story

By now, I have told so many dribs and drabs of my own story that I feel lost and overwhelmed by the vast number of stories that do exist! Nevertheless, as I asked at

the beginning of this research voyage – where does one begin one's story, and where does one end? Maybe there was no beginning to this story – maybe it was not meant to have a beginning or an end, but rather meant to be written as one goes along, and so adding to this rich story and making meaning as one goes along. Needless to say, after all the stories that we have told, I still do not know how to convey to you what I have learned. Leyna has occupied a very special place in my heart, and I will always be thankful for what she has meant to me. She gave my life purpose; she showed me what I am capable of and made me care deeply for others. Albert Einstein's quote that I used at the beginning of part 2 summarises exactly how I feel about her presence in my life. No matter how difficult it has been, she has given me faith and made me believe that God does exist, and that He does have a plan with our lives. I do not know how to thank her for that, or if she will ever know the amount of change and growth that she has made possible in our lives. She has made me realise how important it is to cherish where you come from, in order to know where you are going. She also made me see the lighter side of things – that one should not always be so serious, but rather use laughter as a remedy when times are tough.

A concluding reflection

When I asked my family what they thought Leyna would say to us if she were able to, they found it difficult to answer. And after they thought about this for a while, this was their answer: They thought that she might say that she loves us, and thank us for accepting her just the way she is. We never deserted her, but did the best that we knew how to do, and tried to make her part of as many things as we could.

Mother: *I think she loves us very much … and I think she would thank us for accepting her … we never rejected her … We have tried to make her part of as much as we could …*

My feeling was that she would probably tell us to relax, and not to take things so seriously. Knowing her humorous personality, my father added that she would probably joke about things. Lastly, we thought that she might communicate her real feelings so that we would know exactly what she was feeling, and not what we thought she was feeling. She would want us to help her with what she really wants, and not act on our own assumptions.

When asked whether we would rather have had a life without knowing her, not one of us said that we would have chosen it differently if we could. And *that* is an alternative story.

Part 5

A reflection on the alternative stories and the way forward

Heaven's very special child

A meeting was held quite far from Earth!
It's time again for another birth.
Said the Angels to the LORD above,
This Special Child will need much love.

His progress may be very slow,
Accomplishments he may not show.
And he'll require extra care
From the folks he meets down there.

He may not run or laugh or play,
His thoughts may seem quite far away,
In many ways he won't adapt,
And he'll be known as handicapped.

So let's be careful where he's sent,
We want his life to be content.
Please LORD, find the parents who
Will do a special job for you.

They will not realize right away
The leading role they're asked to play,
But with this child sent from above
Comes stronger faith and richer love.

And soon they'll know the privilege given
In caring for their gift from Heaven.
Their precious charge, so meek and mild,
Is HEAVEN'S VERY SPECIAL CHILD.

Masionilla (1981)

We have come to the last part of our voyage. The reason that I started this part with the above poem is that it resonates so well with the stories that we have told and the

meaning that we have made of autism in spite of our difficult circumstances. In this part, I will start by giving a brief overview of the discoveries we have made during this voyage. Thereafter, I will give my own reflections on the process, and explain how it has shaped me both as an inquirer and as a family member of Leyna, a person with autism. I will conclude this voyage by attending to the implications of these discoveries towards future voyages about autism.

Answering my research curiosity by sharing the main themes

After all the alternative stories that were told in Part 4, my research curiosity was indeed satisfied. Before continuing with the discussion on how I attempted to answer my research curiosity, I want to repeat the question about which I was curious:

> What are the alternative experiences or influences that the girl with autism spectrum disorder had on the co-storytellers' lives? (As opposed to the problem-saturated stories).

Firstly, rich, alternative stories about the way in which Leyna influenced my own and the co-narrators' lives do exist, as was seen in the numerous accounts provided in Part 4. Although problem-saturated stories were told, I rather wanted to reframe them to stories of hardship and courage. Since the family told a tale of coping and unconditional love despite their difficult reality, I called the first section in Part 4 'The road towards acceptance', as this is an ongoing voyage that challenges one every day. Every co-storyteller gave an account of their way of understanding autism and how they consequently viewed Leyna.

Accounts were given about the strong and bonding relationship that all of us have with Leyna. This contradicts the impairment in social relatedness that people with autism are so often labelled with (as discussed in Part 2). The story-tellers told how they missed her and longed for her when she was not present. They also described her as a 'shadow' when she is around the people she loves, which bore testimony to her curious nature. Other stories they told about our special relationship with her, showed that we feel protective of her, that we love her deeply, and that we enjoy her uniqueness as a person.

Therefore, another theme the co-storytellers elaborated on was her unique personality that adds to this special relationship. In short, she was described as a genuine person who shows others unconditional love in her own innocent, childlike manner. She is therefore both lovable and loving. Other characteristics that were named were her sense of humour, her capacity to enjoy herself, her overall cuteness, and her quirkiness. It was evident that she is a human being just like anybody else – someone who enjoys being fashionable, who appreciates good music and who is curious about what others are up to. Storying her personality traits therefore gave us all the opportunity to celebrate her as a person.

A strong message of raising awareness about autism for others to have a better understanding of this condition was revealed as well. It was evident from the stories that, although the public has become more accepting over the years, there is still an overall lack of understanding and empathy towards people with autism. It was this family's wish that others would try to understand Leyna and others with autism rather than being judgemental.

The last and probably the most meaningful theme was the telling of stories about personal growth and change because of Leyna's presence in our lives. I portrayed each one's story individually, as that is how she influenced that person's life specifically and how that person created meaning for him- or herself from the experience. My father's story told a tale of enrichment, joy, love and protectiveness regarding Leyna. He also made it clear that she had made him become more aware and empathic of others with disabilities – and consequently more vocal as an advocate for autism. My mother's story conveyed themes of patience, strength and endurance – of how Leyna's condition had prepared her for other challenges in life. It had also made her appreciate the small things in life, such as time spent with others. My sister's story was rich with empathy and caring towards others – of how Leyna had helped her to be more sensitive to others' needs. Leyna's teacher spoke about autism in general, and told me that these children make one learn something new every day. Her work with people with autism and with Leyna in particular, in this case, had also made her more appreciative of the blessings in her own life and had made her more compassionate towards parents and families of children with autism. I also shared my

own story of growth, of how her presence had made me see purpose in life and had inspired me to be more appreciative of the time that we have been given here on earth.

All of these themes together formed a collective account of Leyna's influence on our family's life story. All of us have adopted a sense of humour to carry us through life's deepest struggles. Through the telling of the stories we realised this for the first time. This voyage therefore became the first time that all of us spoke about Leyna's influence on our lives. It created an opportunity for us to learn from each other and to understand each other's perspectives more fully.

Finally, through the telling of these stories, we could create this document – a document that has become evidence for the strengthening of the alternative stories about autism. However, there were some limitations to this voyage.

Limitations of this research voyage

One of the first limitations that come to mind when I think back on this voyage, was the way in which the stories still had to conform to scientific ways of writing up research. Munro Hendry (2007, p. 487) suggests "the need to rethink the very understanding of narrative as research because this reduces stories to objects thereby reifying a positivist view of knowledge". Stories had to be broken down into themes (structures), and could not capture the full essence of storying these multifaceted experiences. Although attempts were made to capture all of these lived experiences, it still felt as if I contradicted the postmodern way of creating knowledge in some way.

In addition, there were time constraints. More discussions and stories could possibly have made this a richer document of alternative stories. Although I encouraged them, the co-narrators also did not have time to reflect on paper whether this voyage had made a difference to how they view Leyna, and what effect this documenting process had on their relationship with her.

The voyage was also limiting in the sense that it only gave the account of one family's and one teacher's story. There are probably more families who have a member with autism with much similar stories to share. Although I noted in Part 3 that the purpose of this voyage was not to generalise to the greater population, I am still curious as to

what other rich, alternative stories exist out there, and how they could perhaps in a small way contribute to our ways of viewing disability in South Africa.

Another constraint that I had not anticipated was the availability of the co-narrators. Our father stays in another city and only comes to visit us every three weeks. It took careful planning around his schedule to have the discussion, especially because Leyna also stays with us on the weekends that he is here, and we decided not to involve her in the discussions. With the questions that I had afterwards, I had to communicate with him through electronic mail and on the telephone. Another example of time and availability constraints was the difficulty to get hold of Leyna's teacher. Eventually we decided on a telephonic interview, as the circumstances did not allow us to meet in person. This was not ideal, but we shared some wonderful alternative stories nevertheless. Lastly, I had to have the discussions with my mother and sister together as there was also limited time. This provided an interesting dynamic and surprised me as the atmosphere was inviting of stories.

In the following section, I will share my reflections on this storying process with you – both as a narrative inquirer and as a sister of a person with autism.

The importance of reflection

In Parts 1 and 3 I explained that reflexivity in a narrative study is of utmost importance, because it is a way of monitoring oneself not to influence the findings and jeopardize the credibility of the study. Etherington (2007, p. 599) explains the role of a reflexive practitioner in the following way:

> Reflexivity, although enabling the conduct of ethical relational research, also requires inquirers to come from behind the protective barriers of objectivity and invite others to join with us in our learning about being a inquirer as well as remaining human in our research relationships.

Although this makes the inquirer more vulnerable, the reflexive practitioner actually recognizes the fact that he or she is part of the study and the co-narrators' life stories. It also contributes to the principle of collaboration and mutual power sharing as was discussed in Part 1. I agree with Jootun et al. (2009) that this was indeed a chance to turn subjectivity into an opportunity. Also, as said in the section on validity in Part 3,

it was important for me to become a reflexive inquirer so as to be conscious and continually reminded of what the inquirer also brings to the study.

Reflection and growth as a narrative inquirer

The discussions that I had with the storytellers turned out to be different from what I had expected. It reminded me of Hoffman (1997) who stated that it is not an easy task for the inquirer to be aware of his own self, and even more difficult to be aware of this self during the discussions – "to be conscious of the self that moves in and out of what I call the shared unconscious pool" (p. xiv). It was only in my reflections afterwards that I came to realise that I was not only working with the co-storytellers, but also with myself (De Vries, 2004). This links with Murray's (2008) view of the reflexive process as a forming of identity, as noted in Part 3.

Each of the discussions was different, and circumstances also contributed to the setting. For instance, all the conversations that I had with the co-storytellers turned out to be so long and filled with such rich descriptions that it was not necessary for follow-up discussions. Rather, the co-narrators and I decided that we would read the transcribed data afterwards and add or omit data if we wanted to. This was all part of the collaborative nature of the narrative research paradigm. Afterwards everyone felt that they had expressed the essence of what the experience with Leyna had meant for them.

As I look back, I know I had not been prepared for the initial reaction that the discussions could invite and thought it would be easier than what it was. There were still problem-saturated stories from some of the co-narrators, and I found it difficult to hear them. I did not really know how to handle this, because I had reframed my own story to that of an alternative one, whereas the rest were still on the ongoing voyage towards acceptance. It was after the discussions had been completed that I realised in what a vulnerable position an inquirer can sometimes be in qualitative studies, especially if he or she is very closely involved with all the co-narrators. This links with what is said in Part 3 regarding the interactive voice that Chase (2005) proposes in narrative research – i.e. a voice that recognises the complex interaction between the inquirer's and the co-narrators' voices. The interactive voice (Chase, 2005) helps the inquirer to understand the co-narrators' voices and consequently assists the reader in

understanding the overall story that the voices tell. It was not always easy to use the interactive voice, and, after reflection, I found that I had sometimes used the authoritative voice, as described below.

In short, by using the authoritative voice, the inquirer combines his or her voice with the co-narrators' ones, thereby not using the co-storytellers' voices predominantly in the text (Chase, 2005). It was especially difficult for me as an inquirer to sit back and just listen to the stories being told without interfering or interrupting. I did indeed interfere on a subconscious level. However, as soon as I realised I was doing this, I used member checking (Cho & Trent, 2006), where I asked the co-narrators if they agreed with me. Alternatively, I apologised and rephrased the sentence structure into a question asked with respectful curiosity, starting with "I wonder if ..." This had a much better effect on the process, because I did not use my premeditated ideas to influence the other storytellers' accounts. However, this was not always easy. When I had to ask more difficult or uncomfortable questions, I found that I was very uncertain of myself. I afterwards ascribed this to the fact that the questions were of such a personal nature, and could potentially hurt me. I experienced firsthand that I could not hide the 'I' from this voyage, as Dudley-Marling (1996) rightly stated. I realized that I feared I would not hear the stories that I wanted to hear; that I wanted to construct their realities for them. Fortunately, through being a reflexive practitioner, I had come to realise that "[a] strength of narrative research lies in both the individual voice as well as in the collective voices shared across critical research endeavours" (Jones, 2007, p. 33). The strength of the stories lay in those accounts that I did not anticipate – and this made this voyage much richer.

On a personal level, I found the whole research process very enlightening. As I started the voyage, I thought that it would end in a certain way – the way that I wanted it to end. However, the process made me develop in this regard, as even I was surprised at how many stories existed: stories of hardship and of joy. Colleagues warned me that research is not a clear-cut process, and definitely not an easy one. It took me a while to realize this, but I am glad that I did come to this insight. It made me learn something about myself. I realized that I cannot control everything, and that sometimes I should just let the process take its own course. And what wonderful discoveries I made once I understood this!

Moreover, it made me realize that I could not 'hide' certain stories that did not fit into the storyline that I had envisaged, because then it would not be the truth, and the validity of the study would be in question. In Part 3 I raised the question of the definition of truth, and came to my own conclusion. 'The truth' is a relative term, and it means something different for each individual. The accounts that we gave constituted the truth for us, and that is the best we could do. It was not perfect, and we are not perfect – but it was and is real. Therefore, this became a true account of our realities, not sugar-coated with idealistic thoughts, but rather a genuine telling of what it is like living with a person with autism. This process became much more meaningful to me once I came to realize this.

As was discussed in Part 1, when working with the co-narrators I based my approach on narrative therapy principles such as respectful curiosity, double listening and the sharing of power or collaboration in the relationship (Morgan, 2000). My evaluator made me aware that one of the therapeutic tools that I used was that of reframing. In the few instances where problem-saturated stories dominated the co-storytellers' storylines, I curiously asked questions around the incident and tried to reframe them from another person's perspective. In addition, I asked them to write down a reflection afterwards of how they had experienced the process – what it had meant for them and whether it had changed some of their perspectives. Nevertheless, I did send them the transcriptions so that they could read them and make any corrections if they wished to do so. All of them read the transcriptions and no changes were made.

A sister's reflective process: The sharing of stories

The poem with which I started this chapter is one that I came across when I was very young. I still remembered it when I started this voyage, because it touched me deeply. When I read it as a young girl, I felt as if the poet had read my mind, and told me exactly how I was feeling. It took me a few years after that to really accept Leyna's autism as part of her, but I always knew that she had been given to our family for a reason. With acceptance comes peace through which you can really enjoy the moments that you have with the particular person. To have a relationship with a person with autism, to really know that person, is a priceless gift that will change your

life in the long run. I do hope that you (the reader) have learnt as much as I have through this voyage, and that it has given you a measure of hope and encouragement.

It was an affirmative experience to recall all the fond memories that exist about her. One of the things that still bother me is that I could not convey the setting or the atmosphere that existed while we were telling our stories. Although I used triangulation (Cho & Trent, 2006) by writing down words about observations that I made, it still does not feel enough. The challenge involved in transcribing data is that you cannot capture the emotion and the atmosphere that is present when speaking about something so personal – so close to your heart. The overwhelming feelings of love, pride, compassion, and sadness are difficult to describe. These are feelings we do not often share as a family, and this is probably the most valuable thing that I have gained from this voyage. I discovered that joy lies in sharing these experiences, whether they are good or bad; to know you were not alone in these times. Our sense of humour as a coping mechanism was also evident. I realised that my whole family tends to see the lighter side of things, joke about things or act out things that are too difficult to talk about. I once again became conscious of how much laughter and joy we share as a family, and how most of our times together are truly fun.

Yes, and things will continue to be difficult – it is definitely not an easy road ahead. But just imagine the stories that we will be able to tell!

We now come to the last section, where I will discuss the road ahead for autism and narrative research – as I believe these two go hand in hand.

The way forward for narrative research and (dis)ability

It would be of great value if future studies could focus more on including the voices of families with disability in their context, as this could lead to the sharing and re-shaping of stories to lessen the effect of the medical-deficit model on discourses about autism. For instance, Molloy and Vasil (2002, p. 667) propose a "reframing of Asperger's syndrome premised on the inclusion of the voices of those who have been labelled [and who] are rarely incorporated into this accepted body of knowledge". Jones (2007, p. 32), who also makes an appeal for the inclusion of the voices of those with disabilities within research studies, points out that "[i]ndividuals with disabilities

represent 10 to 12 percent of the population, yet their perspective remains relatively absent from the literature". She even proposes alternative forms of narrative inquiry, such as supportive autobiographical ethnography, to be explored in order to give voice to those who have been labelled disabled.

In addition, Billington (2006, p. 1) states that, although his study is primarily directed at professionals, "the intention is to encourage theories and the development of practices which are responsive to the wishes and views of disabled people and as such assist in their 'fight for full equality and social inclusion'". My own research curiosity also made me wonder how many other alternative stories about people with autism exist in South Africa, and what an influence this could have on our own country's discourse about autism spectrum disorders. Although challenging, Allred (2009, p. 353) advocates for people with Asperger's syndrome (AS) to be included in changing the discourse:

> People with AS and those who understand and value their differences and perspectives are best capable of developing this challenge, articulating the nature of reframing and delineating an efficacious form of demedicalization. To the extent that proponents of revision are successful, the identity of those with AS will be returned to its rightful owner – those who have AS.

It is evident that a great need exists among professionals, family members and, most importantly, individuals with disability themselves, to tell their stories and make their voices heard on this topic. It is unfortunate that such a gap in our body of research remains, especially pertaining to bridging the communication barriers that lie between inquirers and people with disabilities: "Unfortunately, this language difference has resulted in the voice of people with disabilities remaining unheard, leaving a crevasse so deep in the literature that our understanding about how power and culture influence our lives is incomplete" (Charlton, 1998; Longmore & Umansky, 2001; Oliver, 1996, cited in Jones, 2007). Nevertheless, this study shows that alternative stories about people with autism do exist, and it is these accounts that need to be storied and told to contribute to the paradigm shift away from the medical-deficit model. Jones (2007, p. 40) suggests the utilisation and incorporation of unique tools "in order to create an accessible research environment for individuals with cognitive, social, behavioural,

and language-based disabilities". If these tools can be developed, an exciting era of research awaits us – especially with regard to narrative ways of working.

This raises questions about the future of narrative research. As mentioned before, Munro Hendry (2007, p. 487) brings the whole concept of narrative 'research' into question, as she proposes the exploring of an "alternative view of narrative as outside of research ... that rethinks research not as a scientific act, but as a spiritual act, one that honors the sacredness of our stories and humanity". By this she does not mean that we should stop doing narrative research altogether, but that we as narrative researchers should rethink our ways of doing research that honours us as sacred humans. She proposes that research should not become a "site of knowledge production," but rather a "site of communion" (Munro Hendry, 2007, p. 496). In other words, she asks other inquirers not to do narrative research with the purpose of reducing it to methodology. She ends her paper by asking: "In what ways can we imagine the future of narrative that does not conceptualize 'research' as separate from and having its own strategies which ultimately become reduced to method. How might we listen, trust, and have faith?" (p. 497). This is a challenge, because we know that there are so many more existing stories that need to be told, especially when it comes to research voyages with people that have disabilities. One thing that I am sure of though, is that "we are enmeshed in a world of narrative; we understand our world and ourselves through narrative" (Murray, 2008, p. 116). This means that there will always be place for the telling of stories – stories to shape our own and others' realities. Moreover, we have seen in Part 2 that there has been a shift to more post-structural ways of gaining knowledge, and this is our beacon of hope for future research voyages.

A final reflection

I started out this voyage with the following questions: How do I convey to you the stories so that you (and I) come to a fuller understanding of the influence that someone with autism spectrum disorder can have on your life? And how do my co-narrators and I give a voice to the person whose voice has been unheard for so long? A part of me feels satisfied that I have answered this for you as the reader, and for myself. However, there is another part of me that still feels unsaturated; that still feels

that I could not capture the full essence of the experiences that we shared with Leyna in our lives. However, I said before that this started as a voyage in the middle of another voyage, and that there was no definite beginning or end to this voyage, as we are still making meaning for ourselves through our experiences every single day.

I am therefore leaving you with the following quote, and wish you providence on your future voyages of making meaning of it all:

> We are not hiding. You search with limited senses and therefore our humanity is camouflaged to you. Be still. Be quiet. Be. We notice you on the glacier. We observe you completely. Language presentation is the barrier to our friendship – not sentience or intellect. We do not speak your language, but you can speak ours. Be still. Be quiet. Be. And now be with us. Our silent and invisible language is that easy to learn. Feel it? Welcome. Our friendship has started.
>
> (Rentenbach, cited in Stillman, 2008, p. 70)

Bon voyage!

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List of Addendums

Addendum A

Letter of ethical clearance

UNIVERSITEIT·STELLENBOSCH·UNIVERSITY
jou kennisvennoot • your knowledge partner

18 August 2009

Tel.: 021 - 808-2687
Enquiries: Sidney Engelbrecht
Email: sidney@sun.ac.za

Reference No. 164/2009

Ms C Pentz
Department of Educational Psychology
University of Stellenbosch
STELLENBOSCH
7602

Ms C Pentz

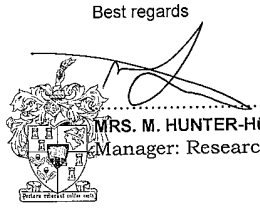
APPLICATION FOR ETHICAL CLEARANCE

With regards to your application, I would like to inform you that the project, *Alternative stories about a girl with autism spectrum disorder*, has been approved on condition that:

1. The researcher/s remain within the procedures and protocols indicated in the proposal;
2. The researcher/s stay within the boundaries of applicable national legislation, institutional guidelines, and applicable standards of scientific rigor that are followed within this field of study and that
3. Any substantive changes to this research project should be brought to the attention of the Ethics Committee with a view to obtain ethical clearance for it.

We wish you success with your research activities.

Best regards



MRS. M. HUNTER-HÜSSELMANN
Manager: Research Information & Strategy

Addendum B

Declaration from external monitor

Sindi Wahl
Educational Psychologist
MEdPsych (Stellenbosch)
HPCSA registration number: PS 0102067

28 September 2009

To whom it may concern

Re: EXTERNAL MONITOR: THESIS: MS C.M. PENTZ: ALTERNATIVE STORIES ABOUT A GIRL WITH AUTISM SPECTRUM DISORDER

This letter serves to confirm that I was an external monitor in the study, *Alternative stories about a girl with Autism Spectrum Disorder*. In the light of the ethical challenges faced in research involving vulnerable individuals, my role was to ensure that this study was rooted in respect for Leyna's[1] human dignity and rights. This was done firstly by having a discussion session with ms Pentz regarding the general ethical considerations, as indicated in the research proposal. I specifically focused on monitoring the process of gaining informed consent, assent and the feedback of the results given to Leyna. Secondly, I reviewed the transcriptions and thesis.

Ms Pentz seemed to be committed to ensuring that Leyna's rights, including psychological integrity and privacy, were protected in the best way possible. Furthermore, the narrative framework and search for alternative stories created a foundation for the respectful way in which Leyna is referred to in the interviews as well as in the thesis. One could argue that if she were able to read or listen to the data and interpretation thereof, the effect would be one of empowerment.

Please feel free to contact me if you have any questions in this regard.

Yours faithfully

Ms S Wahl

[1] Pseudonym

Tel. +27 21 808 4707 - Email: swahl@sun.ac.za

Addendum C

List of guiding questions for discussions

GUIDING QUESTIONS (FRAMEWORK) FOR DISCUSSIONS

- If you think back, what are your fondest memories that you have of times spent with Leyna?
- Are there any funny stories or "Aha" moments that you have shared with her?
- Describe your relationship with Leyna.
- What are the things/characteristics about her that really stand out for you? Why?
- Do you have any stories of particular incidents where she made an impact on your life? Why?
- Were there any changes in your belief systems or views because of her influence in your life?
- Would these changes have been experienced if she did not have autism? Why?
- Which of her characteristics (and specifically her view of life) influenced you the most? Why?
- How did you experience other people's views on autism, specifically relating to Leyna?
- How will you explain Leyna and the autism to a stranger?
- If you could have your life over again, would you rather have chosen not to have her in your life? Why/not?
- Knowing what you know now, would you have preferred it if she was born as a neuro-typical child rather than a child with autism? Why and why not?
- What changes (if any) did she bring about in your own personal life?
- Describe her quality of life (e.g. do you think she is content with who she is, etc.)
- What is your view of autism in South Africa?
- If you could give the people in South Africa one message about knowing a person with autism in your life, what would you say?

Addendum D:

Sample of the transcription of data

Gesprek 1:
Verwantskap: Pa van meisie met ASD
Datum: 08 Augustus 2009

C: Christelle
P: Pa

C: Is daar enige spesifieke ... uhm memories van Leyna wat vir Pappa uitstaan? Soos enige ... oomblikke wat Pappa onthou ... wat Pappa gevoel het ... amper ‘n “aha moment”?

P: Ja, ek dink ‘n ou vergeet ook van hulle ... Daar’s seker ‘n klomp wat, wat ek sal onthou as iemand my net weer herinner of as ek weer net in ‘n situasie kom wat jy weer daaraan dink ... Ag ... goed soos die een keer wat ons ... uuuuuhh ... uuh ... Nature’s Valley toe gery het en ons het mos altyd die gewoonte gehad om te bid vir veilig op die pad en ...

C: Ja ...

P: En toe het ek mos net uit die bloute besluit maar ek gaan nou vir Leyna vra om te bid (grins) toe sê sy “dankie Jisus”

C: (Laughs in rememberance) Okay!

P: So, ek weet nie of sy ... die feit dat sy dit in verband gebring het of watookal met Jesus en so aan, het tog beteken dat sy iewers dit ingekry het een aand as jy by haar gaan sit het om te slaap en ‘n gebedjie saam met haar opsê – dat dit vasgesteek het ... dit was oulik ...

C: Okay

P: Wat nog? Uuuhm ...

C: Sjoe, dis amper daai ... as ek reg verstaan ... daai oomblikke wat jy, jy’t nie eens gedink sy neem iets in nie want sy’s outisties en jy dink ...

P: Ja, ja ...

C: ... alles gaan net verby haar en tog *surprise* sy jou!

P: Ek dink daar was nog sulke geleenthede ... ek dink daar was nog sulke goed meer onlangs wat ‘n woord uitkom wat jy nie gedink het sy gaan sê nie en sulke goed, maar ek kan nou nie dink aan ‘n spesifieke voorbeeld nie ... uuuhhm ... waar wat nog?

Gesprek 2:
Verwantskap: Ma en suster van meisie met ASD
Datum: 09 Augustus 2009

C: Christelle
M: Ma
S: Suster

(Almal lag)

C: Net nog iets wat ek van haar wil sê, is hoe sy mens se liedjies *love* wat jy vir haar opmaak ...

M: Ja, uuuh ...

C: Dit kan die simpelste liedjie wees, maar sy's baie mal daaroor.

M: Mmmm ...

(Lang stilte)

C: Is daar iets in Mamma se persoonlikheid of Mamma se *way of being* wat verander het oor haar?

M: Ja kyk, ek het baie meer geduldig geword ... Ek kan baie meer goeters ... ek het seker 'n baie sterker mens geword.

C: Ja ...

M: Ek kan baie meer verduur ... en met my werk het dit, ek dink ek, dit het my gehelp, want ek is baie geduldig met mense wat bang is of watookal vir tandartse en sulke tipe goed.

C: Sjoe, ek het nog nie so daaraan gedink nie. Jy leer om nogals baie te kan vat.

M: Ja, ja, mmm ...

Gesprek 1:
Verwantskap: Onderwyseres vir 3 jaar
Datum: 26 Augustus 2009

C: Christelle
T: Teacher

T: Leyna ... ja ... sy was ‘n vriendelike meisie gewees ... sy was ‘n baie opgewonde meisie (C lag), en dis ‘n kind wat gelyk het asof sy graag uitgesien het om skool toe te gekom het. Ek het somtyds bussie gery, en as ek haar kom haal het was sy altyd opgewonde gewees om skool toe te kom.

C: Ja ... ja, nee ek moet sê sy’t elke oggend ... in die oggende dan sal sy haar tassie vat dan sal sy by die voordeur sit en wag vir daai bussie. (Lag)

T: Ja nee, sy sy, Leyna is ‘n nie-verbale, leerder gewees, maar ... jy kon tog ... as jy haar onderwyseres is kon jy sien as daar die dag iets fout was met haar ...

C: Ja ...

T: Ek kon dádelik opmerk wanneer, wanneer iets nie lekker was met haar nie ... of daar was byvoorbeeld, wanneer haar voet seer was, het sy gehink en gepink skool toe gekom, maar sy sou tog vir jou gewys het ... of sy sou haar voet opgelig het na my hande toe, of sy sou my bewus gemaak het van haar voet is ... ongemaklik of iets ... is nie lekker by haar nie ...

C: Ja, so julle het geleer om op ‘n manier met mekaar te kommunikeer, wat nou nie noodwendig verbaal is nie ...

T: Ja nee ...

C: (Onderbreek) Julle kon mekaar verstaan ...

T: Ons kon mekaar verstaan, ons kon presies geweet het wanneer daar fout is ... ons kon presies geweet het wanneer sy nie goed geslaap het die vorige aand nie, ons kon presies geweet het wanneer sy nie wou geëet het nie ...

C: Ja.

T: Uhm, ja, alhoewel jy bou daardie verhouding met jou leerder op ... met die spesifieke kind leer jy, en dis so belangrik dat ons elke kind as ‘n individu ken ...

C: Ja